

# **The Subjective Experience of Individuals Diagnosed with Schizophrenia in the Western Cape, South Africa**

by  
Colette Hamman

*Thesis presented in fulfilment of the requirements for the degree of  
Masters of Science (Psychology) in the Faculty of Science at  
Stellenbosch University*



Supervisor: Prof. Lou-Marié Kruger

December 2017

## **DECLARATION**

By submitting this thesis/dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

December 2017

## ABSTRACT

Epidemiological research highlights the severity of the symptoms and outcomes associated with a diagnosis of schizophrenia; the burden of which is increasing substantially in many developing countries such as South Africa. Numerous scholars have been critical of the existing research on schizophrenia. It seems that, although the biological underpinnings of schizophrenia are commonly acknowledged, a psychological and subjective perspective on the pathogenesis of schizophrenia has not adequately been incorporated into research of this diagnosis in developing countries.

Against this background, this study aimed to achieve a deeper and richer understanding of the subjective experience of a diagnosis of schizophrenia in South Africa. This aim was achieved by exploring how a group of individuals from the Western Cape, South Africa, experience and understand the diagnosis of schizophrenia and its associated symptoms. Informed by a social constructionist theoretical perspective, this study employed a multiple case study design to yield qualitative data. In-depth, open-ended, semi-structured interviews were conducted with twelve people diagnosed with schizophrenia. The transcribed interviews were analysed by implementing social constructionist grounded theory, with interpretations informed by relational psychoanalysis and discursive psychology.

Interviews with people carrying this diagnosis uncovered traumatic histories of abuse and submission, highlighting the need to take individual histories seriously, even in people with a diagnosis of schizophrenia. While all of the participants clearly had psychotic experiences, they also experienced rich and diverse emotional worlds often in reaction to disturbed and disturbing intersubjective fields. A complex and vicious cycle of fear, anxiety, and paranoia; shame, anger, and aggression; loneliness and isolation; sadness and even more shame, emerges - not necessarily captured by the diagnosis of schizophrenia. Despite their traumatic experiences and in contrast to their complex experiences of emotional distress, participants, when discussing their diagnosis, quite explicitly and implicitly adhered to a medical discourse of schizophrenia. Informed by this medical model, they constructed themselves as abnormal and as having a dysfunctional brain, which needs to be medically treated. Lastly, caring for others and being cared for by others seemed to be very important for restoring a sense of humanity. This care was mainly provided by families, rather than in the context of the medical model.

I argue that, despite the fact that the diagnosis of schizophrenia is helpful and facilitates the medical treatment of the person, it can also obscure some of the very complex emotional experiences of some very traumatised, scared, ashamed, angry, lonely, and sad individuals who carry this diagnosis. This often entails that these people are not dealt with as complex human beings who have been hurt and also leads to them not defining themselves as such. Integrated models are suggested to recognise the suffering behind this diagnosis; these models include subjective and psychological perspectives on the pathogenesis of schizophrenia that promise a caring and humanising approach in a clinical setting.

**Keywords:** schizophrenia, medicalisation critique, emotional distress, social constructionism, social constructionist grounded theory, South Africa

## OPSOMMING

Epidemiologiese navorsing beklemtoon die erns van die simptome en uitkomstes wat met 'n diagnose van skisofrenie geassosieër word, waarvan die las aansienlik toeneem in vele ontwikkelende lande soos Suid-Afrika. Vele skoliere is krities oor die huidige navorsing op skisofrenie. Dit blyk dat die biologiese meganismes van skisofrenie algemeen erken word. Nuwe konsepsualiserings van die diagnose wat 'n sielkundige en subjektiewe perspektief op die patogene van skisofrenie beklemtoon, word egter nie voldoende in navorsing in ontwikkelende lande geïnkorporeer nie.

Teen hierdie agtergrond, het die huidige studie beoog om 'n dieper en ryker begrip van die subjektiewe ervaring van 'n diagnose van skisofrenie in Suid-Afrika, te verkry. Hierdie doel is behaal deur te ondersoek hoe 'n groep individue van die Wes-Kaap, Suid-Afrika, die diagnose van skisofrenie en simptome wat geassosieër word met die diagnose, subjektief ervaar en verstaan. Hierdie studie is vanuit 'n sosiaal-konstruksionistiese perspektief (*social constructionist perspective*), tesame met 'n veelvuldige gevallestudie ontwerp (*multiple case study design*), uitgevoer, om kwalitatiewe data te lewer. In-diepte, semi-gestruktureerde, oop-einde onderhoude is met twaalf mense wat gediagnoseer is met skisofrenie, uitgevoer. Daarna is die getranskribeerde onderhoude deur middel van sosiaal-konstruksionistiese gegronde teorie (*social constructionist grounded theory*) geanaliseer, met afleidings wat deur relasionele psigoanalise (*relational psychoanalysis*) en diskursiewe sielkunde (*discursive psychology*) verryk is.

Die onderhoude het traumatiese geskiedenis van mishandeling en onderdanigheid getoon. Dit beklemtoon die noodigheid om 'n individu se geskiedenis ernstig op te neem, selfs in mense wat met skisofrenie gediagnoseer is. Die onderhoude het verder getoon dat, terwyl al die deelnemers duidelik psigotiese ervarings gehad het, hulle ook ryk en diverse emosionele wêreld ervaar wat dikwels in reaksie tot versteurde en vreesaanjaande intersubjektiewe velde plaasgevind het. 'n Komplekse en bese kringloop van vrees, angstigheid en paranoia, skaamte, woede en aggressie, eensaamheid en isolasie, hartseer, en nog meer skaamte, verskyn - wat nie noodwendig deur die diagnose van skisofrenie beskryf word nie. Dit het ook voorgekom asof, tenspyte van hul traumatiese ervarings en in teenstelling met hul komplekse emosionele ervarings, pasiënte se besprekings van hul diagnose, implisiet en eksplisiet aan die mediese diskoers van skisofrenie voldoen het. Volgens hierdie mediese model, konstrueer

deelnemers hulself as abnormaal en in besit van 'n disfunksionele brein wat medies behandel moet word. Laastens, blyk dit of sorg vir ander en om versorg te word deur ander, baie belangrik is om 'n sin van menslikheid te herstel. Hierdie sorg was hoofsaaklik deur families, eerder as in die konteks van die mediese model, voorsien.

Ek argumenteer dat, tenspyte van die feit dat die diagnose hulpvaardig is en dit die mediese behandeling van die persoon fasiliteer, dit ook sommige van die komplekse emosionele ervarings van getraumatiseerde, bang, skaam, kwaad, eensaam en hartseer individue wie die diagnose dra, kan versteek. Dit behels dan dikwels dat hierdie persone nie behandel word as komplekse mense wie seergekry het nie en ook nie hulself as dit ervaar nie. Geïntegreerde modelle word voorgestel wat die lyding wat met 'n diagnose van skisofrenie gepaardgaan, erken. Dit sluit subjektiewe en sielkundige perspektiewe op die patogenese van skisofrenie in en beloof 'n versorgende en menslike benadering in 'n kliniese omgewing.

**Sleutelwoorde:** skisofrenie, medikalisering kritiek, emosionele bedroeftheid, sosiaal-konstruksionistiese perspektief, sosiaal-konstruksionistiese gegronde teorie, Suid-Afrika

## ACKNOWLEDGEMENTS

Such indeed is the conditions of things... I do know that however long I did so, I would not get anywhere near to the bottom of it. Nor have I ever gotten anywhere near the bottom of anything I have ever written about... And, worse than that, the more deeply it goes the less complete is. It is a strange science whose most telling assertions are its most tremulously based, in which to get somewhere with the matter at hand is to intensify the suspicion, both your own and that of others, that you are not getting it quite right (Geertz, 1973, p. 29).

During the process of completing this thesis, I often felt like I was not getting it quite right and struggling to reach the bottom of it. I still do not feel that I got close to the bottom of it. However, my suspicion and curiosity have been intensified and I will continue to try to get close to the bottom of it, thanks to the following people:

- My research supervisor, Prof. Lou-Marié Kruger – who continues to inspire me with her compassionate, refreshing and complex contributions to the field of psychology.
- The members of the Schizophrenia Research Unit, specifically Prof. Emsley, Dr. Kilian, Sr. Smit, and Mr. Moosa – for making this study possible by being so welcoming, helpful and supportive.
- The Hamman family (including pets) – who have each, in their own way, contributed to who I am today and to this piece of work.
- My friends, in particular Marguerite – for their wit and reminding me to live my life in between writing up this thesis.
- Ruaan – for always being there for me and my neuroses.
- My fellow students and colleagues – because of you, I am excited about the future of psychology in South Africa.
- The participants of this study – for sharing their stories of “skoonheid en verskrikking” (beauty and terror).

## **STATEMENT REGARDING FINANCIAL ASSISTANCE**

I hereby gratefully acknowledge the financial assistance received from the Harry Crossley Foundation for this thesis. Opinions given or conclusions reached in this work are those of the author and are not necessarily to be attributed to the Harry Crossley Foundation.



## LIST OF CONTENTS

<b>DECLARATION</b>	<b>i</b>
<b>ABSTRACT</b>	<b>ii</b>
<b>OPSOMMING</b>	<b>iv</b>
<b>ACKNOWLEDGEMENTS</b>	<b>vi</b>
<b>STATEMENT REGARDING FINANCIAL ASSISTANCE</b>	<b>vii</b>
<b>LIST OF CONTENTS</b>	<b>viii</b>
<b>CHAPTER ONE: INTRODUCTION</b>	<b>1</b>
Research rationale	5
Research aim and objectives	6
Outline of subsequent chapters	7
<b>CHAPTER TWO: THEORETICAL FRAMEWORK</b>	<b>8</b>
Social constructionism	8
Social constructionism in general	8
Social constructionism in this study	10
<b>CHAPTER THREE: LITERATURE REVIEW</b>	<b>12</b>
The medicalisation of mental illness	12
A brief history of the development of the diagnosis of schizophrenia	14
Conceptual analysis	14
Clinical picture	17
Etiological considerations	17
The subjective experience of mental illness	18
The subjective experience of the diagnosis of schizophrenia	19
Theoretical research	21
Empirical research	21
South African research	24
<b>CHAPTER FOUR: METHODOLOGY</b>	<b>28</b>
Methodology	28
Research aim and objectives	28
Research design	28
Qualitative research	28
Case study	29
Research setting	30
Stikland Hospital	30

Schizophrenia Research Unit	30
Participants	31
Sampling and recruitment	31
Socio-demographic details	32
Data collection instrument and procedure	33
Data management	36
Data analysis	37
Social constructionist grounded theory	37
Relational psychoanalysis and discursive psychology	40
Processes of validation	41
Researcher reflexivity	43
Ethical considerations	45
General ethical considerations	46
Specific ethical considerations	47
<b>CHAPTER FIVE: RESULTS AND DISCUSSION</b>	<b>48</b>
Introduction	48
Results and discussion	48
Historical selves	48
DJ	48
Leo	50
Eugene	51
Lisa	52
Power	53
Boom Boom	54
Rudy	55
Noli	56
Savanna	58
Kloeks	59
Jappie	59
Pieter	61
Summary	61
Complex emotional worlds	63
Fear, anxiety and paranoia	63
Shame	66
Anger and aggression	71
Loneliness and isolation	74
Sadness	78
Summary	82
Medical discourse	84
The abnormal person	84
The dysfunctional brain	86
Medical intervention	90

The medicated body	94
The diathesis-stress model	97
Summary	98
Care	100
Caring for others	100
Being cared for by others	102
Summary	103
Conclusion	104
<b>CHAPTER SIX: CONCLUSION</b>	<b>106</b>
Aim and objectives of the study	106
Summary of findings	107
Limitations of the study	108
Implications of the study and more recommendations	109
Working towards new understandings of the diagnosis of schizophrenia	109
Interventions/treatments	110
Future research on schizophrenia	111
<b>REFERENCES</b>	<b>113</b>
<b>APPENDICES</b>	<b>144</b>
Appendix A1 & A2: Participant recruitment material	144
Appendix B1 & B2: Socio-demographic questionnaire	146
Appendix C1 & C2: Interview schedule	148
Appendix D1 & D2: Participant informed consent form	154
Appendix E: Ethical approval notice	162
<b>LIST OF TABLES</b>	
Table 1: Study participants	33

## CHAPTER ONE: INTRODUCTION

Schizophrenia is generally considered to be one of the most severe mental disorders (Mosotho, Louw, & Calitz, 2011). This is because a diagnosis of schizophrenia is characterised by a chronic course and outcome (Mueser & McGurk, 2004), a combination of multiple etiologies (Motlana, Sokudela, Moraka, Roos, & Snyman, 2004) and the large burden it imposes on affected individuals, their caregivers, and public health services (Chan, 2011; Molefi, 2009; Mosotho et al., 2011). Figures relating to the global incidence of people diagnosed with schizophrenia suggest that around 3% of the population will have at least one psychotic experience which necessitates the involvement of mental health services (Geekie & Read, 2009), with the global prevalence of schizophrenia in the year 2008 estimated to be approximately 1% (Asmal et al., 2011).

The onset of schizophrenia usually occurs during late adolescence or early adulthood, with most people affected between the ages of 17 and 25 years old (Geekie & Read, 2009). Often the onset is progressive, but it can also be in the form of an acute “psychotic break” (Berzoff, Flanagan, & Hertz, 2011). The course of the illness is also variable, with people undergoing an active psychotic phase either followed by recovering with little residual effect, restabilising at a lower level of functioning, or remaining chronically psychotic (Berzoff et al., 2011). It has been shown that the most common course of the illness includes a series of acute psychotic episodes with increasing personality deterioration (Berzoff et al., 2011). The stages of schizophrenia typically include the risk stage, prodrome of schizophrenia, onset of psychosis and the chronic disability stage (Khamker, 2015). This is part of a trajectory marked by transitional periods: the individual transitions from being “healthy” to a prodromal state characterised by non-psychotic behavioural disturbances. This is followed by attenuated psychotic symptoms not requiring treatment, whereafter the individual typically converts to experiencing psychotic symptoms that prompt initial presentation for treatment, leading to a formal diagnosis of schizophreniform disorder and then schizophrenia (Gardner & Nasrallah, 2015). Suicide is often the leading cause of premature death in people diagnosed with schizophrenia, as 20-40% of these people attempt suicide at some point in their lives (Walsh, Hochbrueckner, Corcoran, & Spence, 2016). It follows then that schizophrenia is amongst the top ten leading causes of disability worldwide (Balaji et al., 2012; Baumann, 2015; Davidson, 2003).

Historically, studies of schizophrenia have, to a large extent, discounted the possibility of recovery (Andreasen, 1997). More recently, psychiatrists and psychologists, for instance those associating themselves with the Recovery Movement, have started to challenge the previously widely-held view of a pessimistic prognosis (Davidson, 2003). The Recovery Movement emphasises the need for a person diagnosed with schizophrenia to be supported in a rehabilitation model that focuses on self-determination, self-sufficiency and the potential for growth, together with someone who encourages hope in recovery (Ahern & Fisher, 2001). A person living with a diagnosis of schizophrenia can now be viewed as being a person apart from his or her illness, someone who responds uniquely to the illness, and someone who may have the ability to recover from it (Davidson, 2003). Considerable data from high-income countries also support the value of early intervention following the first episode of the illness (Khamker, 2015), perhaps suggesting that outcomes can be varied.

The burden of chronic non-communicable diseases (including mental illnesses) is said to be particularly substantial and on the increase in low- and middle-income countries (Lund et al., 2010; Lund, Petersen, Kleintjes, & Bhana, 2012; Mayosi et al., 2009, 2012). This includes South Africa, with its socioeconomic inequalities and poorly resourced public mental health services (Motlana et al., 2004; Western Cape Department of Health, 2013). The limited research in Africa regarding the prevalence of neuropsychiatric disorders, under which schizophrenia is classified, suggests that the prevalence is at least comparable with that of the international community (Hugo, Boshoff, Traut, Zungu-Dirwayi, & Stein, 2003). It was estimated that neuropsychiatric disorders might contribute up to 18% of the total disease burden in Africa by the year 2020 (World Health Organization, 2001). These neuropsychiatric disorders significantly contribute to morbidity, loss of productivity, mortality, and lifelong health care costs, specifically in rural communities (Mayosi et al., 2012). Relapse prevention remains a challenge to the long-term treatment of schizophrenia (Asmal et al., 2011), with many patients in sub-Saharan Africa remaining undiagnosed, or when diagnosed, not having access to sustainable and affordable medical care (Dotchin & Walker, 2012; Seedat et al., 2008). This may place patients at risk for victimisation, homelessness, and poor mental health outcome (Cohen, Patel, Thara, & Guereje, 2008).

Given the severity of the symptoms and outcomes associated with a diagnosis of schizophrenia, it is not surprising that “schizophrenic madness has had more explanations

thrown at it and been the object of more attempts to render meaningful than has any other mental illness” (McGlashan and Hoffman, cited in Kaplan & Sadock, 1995, p. 957). In popular discourse, schizophrenia is often viewed as the prototypical manifestation of madness, invoking images like lunacy, incoherence, homelessness, violence, isolation, wild laughter, pitifulness, catatonia, and meaninglessness (Wood, 2013) and triggering reactions of unease, anxiety, and even fear (Geekie & Read, 2009). However, most of what lay people think they know about a diagnosis of schizophrenia is limited and/or problematic, with the stigma of schizophrenia in the community acting as a barrier to the rehabilitation process of patients and families with a member who suffer from schizophrenia (Motlana et al., 2004). It is argued that a poor understanding of this diagnosis in the South African context adds to the burden (Motlana et al., 2004).

Clinically, the schizophrenia spectrum disorders<sup>1</sup> are referred to as psychiatric diagnoses which consist of a complex collection of major mental disturbances with a combination of unknown etiologies (Read, Doku, & Aikins, 2015). Although there is no pathognomonic or syndrome-defining clinical feature of the schizophrenia spectrum disorders, the American Psychiatric Association (APA)’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (5th ed.; DSM-5; APA, 2013), states that schizophrenia spectrum disorders “are defined by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganised thinking (speech), grossly disorganised or abnormal motor behaviour (including catatonia), and negative symptoms” (p. 187). The common clinical features are thus thought to include disturbances in thinking, perceiving, feeling, behaviour, sense of self, and ability to function in society, causing some to claim that “it is a disruption of these faculties, which might be considered to be the core of what it is to be human” (Baumann, 2015, p. 540). Schizophrenia spectrum disorders include, for instance, the brief psychotic disorder that lasts more than 1 day and remits by 1 month. Also, schizophreniform disorder is characterised by a symptomatic presentation equivalent to that of schizophrenia except for its duration (less than 6 months) and

---

<sup>1</sup> In this study, I use the term schizophrenia to refer to the psychiatric diagnosis of schizophrenia under the schizophrenia spectrum disorders in the DSM-5 (APA, 2013). This term is used in order to aid general comprehension and to identify individuals who have met the DSM diagnostic criteria, even while it is exactly this diagnosis that is under exploration. While I use the term here descriptively, I acknowledge that the use of professionally clinical terms such as “schizophrenia”, “psychosis” and “patient” are controversial and laden with medical overtones that suggest that the experiences that these terms refer to are seen as “symptoms” of a “patient” suffering from a “mental disorder” (Dillon & May, 2002; Russo, 2001; Wood, 2013).

the absence of a requirement for a decline in functioning. Schizophrenia lasts for at least 6 months and includes at least 1 month of active-phase symptoms. In schizoaffective disorder, a mood episode and the active-phase symptoms of schizophrenia occur together and were preceded or are followed by at least 2 weeks of delusions or hallucinations without prominent mood symptoms (APA, 2013).

Corresponding to the diversity in course, outcome and clinical presentation, reviews of the literature highlight reoccurring shifts between biological and psychological explanations of schizophrenia, leading up to a recent emphasis on the biological mechanisms involved in the pathogenesis of schizophrenia (Baumann, 2010). For example, a lot of attention has been paid to the use of different pharmacological medications in minimising symptoms associated with this diagnosis (Patel, 2005; Taylor & Ng, 2012). This has greatly advanced our knowledge. The biomedical approach, although clearly contributing to the understanding and treatment of those diagnosed with schizophrenia, has recently again come under scrutiny with some claiming that “the voice of the sufferer is silenced by virtue of being translated into the language of mental pathology, and the context of the suffering, is written out of the story” (Speed, Moncrieff, & Rapley, 2014, p. xv). Such critics also claim that “an adequate understanding of the phenomena of the psychoses remains elusive” (Baumann, 2010, p. 279) and have argued that, while biomedical advances should be acknowledged, it is also crucial to respect the experiences and narratives of those diagnosed with severe mental illnesses such as schizophrenia (Cohen, 2008; Davidson, 2003; Estroff, 1989, 2004; Geekie, Randal, Lampshire, & Read, 2012; Geekie & Read, 2009; Jenkins & Barrett, 2004; Karp & Birk, 2013; Kirmayer, Lemelson, & Cummings, 2015; Kleinman, 1988b, 2015; Robbins, 1993).

It has been asserted that we still know little about the personal experience of schizophrenia, with few qualitative studies exploring how people diagnosed with schizophrenia experience and understand their psychological distress and the subsequent diagnosis (Walsh et al., 2016). As a result, there has been a recent international proliferation in qualitative studies focusing on the subjective experience of individuals diagnosed with schizophrenia (De Wet, 2013; Read et al., 2015). Geekie and Read (2009) state that the growing body of literature looking at aspects of the experience of psychosis shows that a diagnosis of schizophrenia and the symptoms associated with the diagnosis interrupt the lives of people who must continue to struggle to find and create security and meaning.

These international studies may, however, not be relevant to individuals in low- and middle-income countries, not capturing the complexities of the experience of a diagnosis of schizophrenia in the developing world (Baumann, 2010; De Wet, 2013; K & Duncan, 2006; Read et al., 2015). A large portion of studies on schizophrenia in Africa still only implement standardised, quantitative methodology (Read et al., 2015). It seems then that, while the biological underpinnings of schizophrenia are commonly acknowledged, new conceptualisations of the disorder (such as Baumann, 2004; Garrett & Turkington, 2011) highlighting the importance of also incorporating a psychological and subjective perspective on the pathogenesis of schizophrenia, have not adequately been incorporated into research in developing countries (Baumann, 2010; Read et al., 2015).

This study, therefore, explored how individuals subjectively experience and make sense of a diagnosis of schizophrenia and the symptoms associated with this diagnosis, specifically in the context of a developing country like South Africa. Simply stated, this study is about exploring how individuals diagnosed with schizophrenia in the Western Cape experience and understand their diagnosis and the symptoms associated with the diagnosis. This qualitative study engaged with the participant's view of his or her world, and is in this way congruent with the therapeutic move to understand individuals as "active agents in their own recovery" (Jackson & Iqbal, 2000, p. 88) within their own terms of reference, personal histories of attachment to others and development of self (Hirschfeld, Smith, Tower, & Griffin, 2005). It is hoped that this work can serve as a construction of useful knowledge that "constitutes an essential bridge between sufferer and helper - a platform for mutual understanding and for organising meaningful interventions" (Kirmayer et al., 2015, p. 648).

### **Research Rationale**

I argue that the study of how individuals diagnosed with schizophrenia, in the Western Cape, South Africa, experience and understand their diagnosis and the symptoms associated with the diagnosis, is important for the following reasons: firstly, epidemiological research highlights the severity of the symptoms and outcomes associated with a diagnosis of schizophrenia (the burden of which is increasing substantially) together with other chronic non-communicable diseases, in many developing countries such as South Africa. Secondly, numerous scholars have been critical of the existing research on schizophrenia, claiming that, despite the proliferation in quantitative studies, it is unclear to what extent current research has achieved a sophisticated and



comprehensive understanding of the emotional distress of individuals diagnosed with schizophrenia and how they make meaning of this distress. The relevance of diagnostic categories such as schizophrenia, specifically in developing countries, has also been questioned. Thirdly, on recognising the suffering behind this diagnosis, new conceptualisations of a diagnosis of schizophrenia have suggested the importance of also incorporating a psychological and subjective perspective on the pathogenesis of schizophrenia, especially in developing countries, while acknowledging the biological underpinnings.

It therefore seemed necessary to acquire more in-depth, nuanced and textured understandings of the subjective experience of individuals diagnosed with schizophrenia, specifically in the context of a developing country like South Africa. Such research is needed to improve the knowledge base in order to make valuable and helpful contributions to future policies, interventions and research strategies.

### **Research Aim and Objectives**

Flowing from the rationale for the current study, it is anticipated that this study can lead to a deeper and richer understanding of the subjective experience of a diagnosis of schizophrenia in South Africa. In order to achieve this goal, the following objectives were pursued:

- To explore how a group of individuals from the Western Cape, South Africa, subjectively experience the diagnosis of schizophrenia and the associated symptoms. In other words, how do they themselves describe their emotional distress?
- To investigate how this group of individuals make sense of, or understand, the diagnosis of schizophrenia and the symptoms associated with it. In other words, how do they construct their emotional distress?

Implicit in these objectives, is the resolution to make individuals and their diverse experiences visible within scientific literature, while being aware of the “social and political implications of the research, accompanied by a commitment to using the research process to benefit the research participants” (McLeod, 2003, p. 72). The study was therefore informed by a social constructionist theoretical perspective, a qualitative research design, a semi-structured interview schedule, and social constructionist grounded theory as method of data analysis.

### **Outline of Subsequent Chapters**

Flowing from the Introduction in Chapter One, Chapter Two focuses on the social constructionist theoretical framework implemented in this study. Thereafter, the literature review in Chapter Three considers three different bodies of literature concerned with a diagnosis of schizophrenia: the medicalisation of mental illness, a brief history of the development of the diagnosis of schizophrenia, and the subjective experience of mental illness. Chapter Four details the methods employed towards achieving the goal of this study. The results of the study and the discussion thereof in terms of relevant constructs in the literature follow in Chapter Five. Lastly, in order to round off this in-depth exploration of the subjective experience of individuals diagnosed with schizophrenia in South Africa, Chapter Six includes some tentative concluding remarks, recommendations for further research and interventions, as well as reflections on the limitations of the study.

## **CHAPTER TWO: THEORETICAL FRAMEWORK**

Silverman's (1993) well-known statement that "without theory there is nothing to research" (p. 1) is a powerful reminder that research always, inevitably, is shaped by theory. In other words, the particular point of departure - the explicit or implicit theoretical framework - determines which different aspects of the phenomenon under investigation are attended to or not attended to (Terre Blanche, Durrheim, & Painter, 2006). In this chapter, I elaborate on the social constructionist theoretical framework that informs the choice of focus, the method utilised to investigate, as well as the ways of understanding and presenting findings.

### **Social Constructionism**

#### **Social Constructionism in General**

Social constructionism, a postmodern and poststructuralist way of understanding the world (Andrews, 2012), has been shaped by various social science disciplines and perspectives. Interest in constructionism has developed out of taking a critical stance towards the positivist tradition in science as well as essentialist or realist theories of "truth" and meaning and has in recent years become an increasingly influential approach (Burr, 2003; Davidson, 2003). Essentialist theories rely on a concept of true essences, with the assumption that is also found in positivism, that we can know these truths objectively (Cohen, 2008). Although the exploration of meaning has a long tradition within psychology, the constructionist framework can be traced to the work of American psychologist George Kelly, who argued that individuals implement a personal construct system in order to make sense of their realities (Davidson, 2003).

Social constructionism challenges essentialist or realist theories by theorising that people are socially constructing reality at all times. Rather than searching for the "truth" of social/psychological events, social constructionism highlights the ways in which meaning is negotiated, the way in which those in power often determine meaning, and how meaning is represented in language (Hare-Mustin & Marecek, 1990). In other words, in challenging the scientific notion of positivism, social constructionism is an active and subjective approach of becoming involved in and trying to understand the ways in which different people make meaning of their lives in different contexts (Lesch, 2000). By focusing on the ways in which human experience are mediated linguistically, historically and culturally, it does not mean that we can never really know anything, but rather suggests that there exist "knowledges" instead of

a “knowledge” (Willig, 2013). From a social constructionist point of view, when people talk about their experiences, they are not simply describing their inner reality (like in phenomenological research) or providing information about social/psychological processes (as in realist research), but rather are thought to present the various ways in which lived experience are impacted upon by societal discourses, as well as the consequences for those who are affected by these discursive constructions (Willig, 2013). While social constructionism is defined in different ways, four key elements are generally included in such definitions: (1) the view that knowledge is sustained through social processes, (2) taking a critical stance towards general knowledge, (3) historical and cultural specificity, and (4) the view that knowledge and social action go together (Burr, 2003).

Firstly, knowledge is thought to be produced through social interactions in a particular time and place (Burr, 2003). In this way, the social constructionist perspective takes a strong focus on the social and relational effects on the construction of reality (Owen, 1990), rather than basing people’s “frameworks of meaning” (White, 2004, p. 11) solely on private cognitive processes inside the individual (Cohen, 2008). As the research process itself is a form of social interaction, the social constructionist perspective implies that the knowledge which is constructed during research is one representation of reality that reflects an interaction between the researcher and participant in that particular time and place (Charmaz, 1995). It follows then that research informed by social constructionism focuses on trying to make sense of individuals’ identities by identifying the different ways in which they construct their social realities through their collected life stories over time (Willig, 2001). This knowledge is then used to identify the implications for human interaction, practice and experience (Willig, 2001).

Secondly, social constructionism challenges positivistic and empirical claims of producing objective knowledge by encouraging a critical and sceptical stance towards what is typically seen as general knowledge (Burr, 2003). While radical social constructionism focuses on the particular reality that is constructed within a specific context, moderate social constructionism (as in this study) typically engages with dominant cultural discourses that pre-exist and shape the ways in which individuals discursively construct knowledge and meaning in specific contexts (Willig, 2013). Particularly relevant here is the belief that categories with which the world is understood (such as the existence of “sane/insane” individuals) do not necessarily represent “true” divisions (Burr, 2003)

Thirdly, this perspective also suggests that people as social beings, with both a subjective and objective reality (Andrews, 2012), are complex constructions influenced by culture and history (Owen, 1990). Knowledge is therefore not seen as universal and eternal, but rather influenced by the values of the individual in a specific social- and political context (Charmaz, 1995; Stoppard, 2000). As power differentials, culture, context, and language are acknowledged and highlighted in this perspective, it makes it very suitable for research in the diverse and complex South African context (Dukas, 2013; Kruger & Lourens, 2015; Kruger, Van Straaten, Taylor, Lourens, & Dukas, 2014).

Fourthly, within this approach it is argued that, because language does not only describe the social reality, but can also be used to understand the social world, language is constructive (Macleod, 2002). As such, the social constructionist perspective focuses our attention on the discourses that exist about a phenomenon, such as the diagnosis of schizophrenia, in a society (Willig, 2001). This means that studying a phenomenon from a social constructionist perspective, includes examining the underlying dominant discourses or “systems of reasoning” (Lesko, 2001) that exist in a society. It is argued that these discourses become a way in which people construct their identities, and can be used by others to make sense of people’s lives (Cohen, 2008) - and in this way inform social action (Willig, 2001).

### **Social Constructionism in this Study**

Social constructionism is a theory that appears to be particularly relevant in the study of illness and health (Parker, 2006). Social constructionist approaches to illness and health focus on an individual’s experiences and understandings of their own illness experience within their specific cultural and social context. It therefore expands the scope of the study of illness and health from a focus on illness behaviours to how people understand and experience these illness behaviours.

The social constructionist literature emphasises that the meaning of an illness (including a mental illness such as schizophrenia) is discursively constructed through the use of language in specific cultural and historical contexts (Willig & Stainton-Rogers, 2008). As such, the experience and meaning of being diagnosed with an illness are thought to be different for different people (Gwyn, 2002; Kirmayer et al., 2015; Parker, 2006). As the narratives of patients regarding their subjective experiences of a diagnosis within their social contexts were up to

recently not of great importance to medical professionals, disregarding to a certain extent the reciprocal relationship between the social context and bodily experiences of a diagnosis (Herbst, 2006), a social constructionist perspective functions to highlight patients' constructions of reality (Treichler, 1999). This does not mean that the biological and genetic underpinnings of the illness are denied, but rather that there is also a focus on how symptoms are interpreted and the illness constructed (Gwyn, 2002).

Consequently, if schizophrenia research focuses on how people experience and make sense of their diagnosis within different social and cultural contexts, new voices can lead to new and alternative meanings of the diagnosis of schizophrenia and symptoms associated with this diagnosis. In this way, this study recognises the importance of also incorporating a psychological and subjective perspective on the pathogenesis of schizophrenia, whilst acknowledging more dominant biomedical knowledge. The focus of social constructionism on fluid personal subjectivity, multiple identities, and conflicting social discourses has been considered vital in obtaining a comprehensive picture of how this diagnosis is subjectively experienced within a particular setting. As such, rather than developing generalisations, this study employed a social constructionist framework together with a qualitative research method, such as social constructionist grounded theory, to pay attention to the rich descriptions of participants themselves. The understanding of participants' personal experiences within their social contexts is emphasised (Willig, 2001).

In summary, the present study, informed by social constructionism, focused on exploring how individuals diagnosed with schizophrenia in a specific South African setting experience and understand their diagnosis and the symptoms associated with their diagnosis. From a social constructionist perspective, individuals' meanings of a diagnosis of schizophrenia will be understood as constructed through the everyday relational context of discourse. In the following chapter, I provide an overview of three bodies of literature concerned with the diagnosis of schizophrenia.

## **CHAPTER THREE: LITERATURE REVIEW**

Research in developing and developed countries suggests that schizophrenia is generally considered to be one of the most severe mental disorders (Mosotho et al., 2011), as this diagnosis is associated with considerable disability (Balaji et al., 2012; Baumann, 2015; Davidson, 2003). In this literature review, I consider three different bodies of literature concerned with the diagnosis of schizophrenia: firstly, I discuss the literature concerned with the medicalisation of mental illness. Secondly, I trace the history of the diagnosis of schizophrenia, critically discussing the development of schizophrenia as a construct. I also specifically look at the clinical picture and etiological theories associated with schizophrenia. Thirdly, I discuss the international theoretical and empirical literature which elucidates the importance of exploring the subjective experience of mental illness, also in South Africa.

Due to the social constructionist theoretical framework and qualitative research design of this study, this brief literature review will not set out to cover all relevant empirical research on, and theories of, the cause, treatment, course and outcomes of schizophrenia in depth. Given my focus on how individuals experience and make sense of a diagnosis of schizophrenia, it is important that the data collection and data analysis are not shaped by existing literature and preconceived ideas. As is typical in social constructionist qualitative research, the empirical literature were incorporated into the results and discussion chapter (Chapter Five), following the “developing independent analysis” (Charmaz, 2006, p. 6), with the researcher assuming a stance of “theoretical agnosticism” (Charmaz, 2006, p. 165) during the stage of theory building (Willig, 2013).

### **The Medicalisation of Mental Illness**

Most definitions of health include the view that “health is the absence of illness and infirmity (freedom from disease, dysfunction, and disability), or health as a positive state of wellbeing (a state of equilibrium, adaptation, harmony, and wholeness)” (Fernandez-Ballesteros, 2003, p. 442). Despite the existing dichotomy between biological and psychological (or cure versus care, nature versus nurture) theories of health and illness, modern Western health care is still dominated by a biomedical interventionist approach (for critical accounts of the biomedical movement, see Deacon, 2013; Moncrieff, 2008; Whitaker, 2010). This science-based medical theory and practice focuses on the internal physiological workings of the body (Gillespie &

Gerhardt, 1995). In this medical model, the terms “disease” or “disorder” often refer to the absence of health, while the terms “illness” or “distress” are preferred when referring to a patient’s subjective experience of a diagnosis (Gwyn, 2002).

The medicalisation critique was one of the most dominant perspectives in the sociology of illness and health during the 1970s and 1980s, reflecting concerns similar to the Anti-Psychiatry Movement of the 1960s. The Anti-Psychiatry Movement mainly argued against the field of psychiatry, viewing the unequal power relationship between doctor and patient and the highly subjective diagnostic process, as oppressive and even coercive (seminal writings include Cooper, 1967; Foucault, 1963; Kleinman, 1988a; Laing, 1960; Rosenhan, 1973; Szasz, 1961). One of the main advocates for the medicalisation critique, Ivan Illich, emphasised a holistic approach to health, including spiritual and personal dimensions needed to cope with illness (Gillespie & Gerhardt, 1995). More recently, Speed et al. (2014) claim that “the neurochemical society that we currently inhabit acts to banish suffering by representing it as a condition arising from bodily dysfunction that needs fixing, rather than a social problem that needs redressing” (p. xv).

Most critiques against the biomedical model of severe mental illness from inside as well as outside the field of psychiatry, revolve around the slow process of understanding and treating mental illness, overdependence on medications and other biomedical treatments, as well as the lack of focus on people’s life worlds and aspirations (Geekie & Read, 2009). Kleinman (2015) writes in the foreword to the recent influential text *Re-envisioning Psychiatry*:

After a half century of serious biological research, it seems that all but the true believers are beginning to lose confidence and are feeling ashamed of the simple fact that we do not understand the pathophysiology of depression, anxiety disorders, bipolar disorder, or schizophrenia. Nor do we possess a single biological test that can be routinely applied in the clinic to diagnose these or other mental disorders – which, given the large investments in biological research, is nothing short of scandalous (p. xvii).

Similarly, Patel (2014), a psychiatrist and global mental health expert, problematises what he calls “the deliberate tilt in the balance between the personal narrative and the biomedical concept, toward the latter” (p. 17). Patel, as well as a disability scholar Davis (2002), contend that mental health experts seemed to have set aside the complexity of the interaction between the



social, cultural, political and historical contexts of suffering behind a diagnosis and as such, have lost touch with the lived emotional suffering of real people in the world, especially in the developing world.

The medicalisation critique has been extended to critiques surrounding current diagnostic systems for mental illness. Andreasen, a prominent American neuropsychiatrist and neuroscientist as well as influential early advocate of operationalism and biological reductionism, describes in hindsight (see her earlier work, Andreasen, 1984) that the unfortunate results of a diagnostic system such as the DSM, is that it can discourage clinicians to get to know their patients as individual people with interesting signs and symptoms (Andreasen, 2007). According to her, this can result in diagnoses that lack validity and have a dehumanising impact on the field of psychiatry (Andreasen, 2007). Other authors, including Hornstein (2013), accept the usefulness of having criteria that distinguish one type of suffering from another, particularly when it can help treatment. However, salient to the current study is Hornstein's (2013) argument that in order to be meaningful, diagnostic categories must stem from lived experience. She contends that the biggest problem with the DSM-5 is that it "continues unchallenged the tradition of adding to a profusion of diagnoses that are already so far away from lived experience as to have little clinical use" (p. 30).

The Anti-Psychiatry Movement, followed by the medicalisation critique of mental illness and the critique against psychiatric diagnostic systems, inform the history of the development of the diagnosis of schizophrenia. The controversial construct of schizophrenia has been conceptualised, theorised and explained in many different ways and has been labelled an "essentially contested concept" (Geekie & Read, 2009). Some have even stated that "disagreement and contestation about meaning, reality and identity may represent the quintessence of schizophrenia" (Estroff, 2004, p. 284).

## **A Brief History of the Development of the Diagnosis of Schizophrenia**

### **Conceptual Analysis**

The full history of traditional scientific conceptualisations of, and approaches to, the diagnosis of schizophrenia is complex and beyond the scope of this thesis. However, a brief analysis of the development of a diagnosis of schizophrenia will be provided in order to grasp something about the range of meanings attached to this diagnosis at different times and in

different contexts. The medicalisation critique informs this discussion of the history of the diagnosis. I continue by critically discussing the development of schizophrenia as a construct and also looking at the clinical picture and etiological theories associated with this diagnosis.

German psychiatrist Emil Kraepelin first made the distinction between disorders of mood - or “manic depression” - and disorders of psychosis - or “dementia praecox” - contributing towards a shift away from earlier social and religious conceptualisations of mental illness toward a more scientific and biological psychiatry (Geekie & Read, 2009; Wood, 2013). Eugene Bleuler, a Swiss psychiatrist, was the first to coin the term “schizophrenia” in 1908, regarding it as a disease wherein mental functions are split, differentiating between “core symptoms” that were seen as pathognomonic and “ancillary symptoms” that can also be exhibited in other disorders (Davidson, 2003). Currently, the former is referred to as “positive symptoms” and the latter as “negative symptoms”. Kraepelin and Bleuler both assumed abnormality of the self to be basic in schizophrenia (Kirmayer et al., 2015). However, in contrast to Kraepelin’s somewhat pessimistic view, Bleuler created a basis for working psychotherapeutically with people who had a psychotic experience and recognised variability in outcome. It has been argued that, although the psychiatric construct of schizophrenia has been challenged since this time, with Jansson and Parnas (2007) commenting that approximately 40 definitions of schizophrenia have been produced, the basic notion of a diagnosis of schizophrenia has remained largely in tact (Geekie & Read, 2009). Following this early work, Freudianism amongst other psychological treatments developed in reaction to re-creating previous dehumanising asylums (Kleinman, 2015). These psychological treatments aimed at humanising health care through an understanding of the biography of the patient and of the therapeutic process (Kleinman, 2015). Freud’s ideas, together with subsequent similar psychoanalytic theories of schizophrenia as caused by faulty parenting and other early childhood experiences, strongly influenced American psychiatry (Chesler, 1972).

The International Pilot Study of Schizophrenia noted that the wide range of symptoms identified as associated with a diagnosis of schizophrenia up until this time in history, led to an over-diagnosis of schizophrenia (Andreasen, 2007). In search for greater reliability in diagnosis, Kurt Schneider played a primary role in shifting the focus to the more “abnormal” - and in this way more identifiable - positive symptoms of schizophrenia during the 1960s and 1970s (De Wet, 2013). His broad categorical approach, together with the arrival of the DSM-III (APA, 1980), signalled an official shift to viewing severe mental disorders as brain diseases diagnosed

according to certain psychiatric diagnostic criteria (Flanagan, Davidson, & Strauss, 2010; Karp & Birk, 2013). This resulted in increased clarity about the symptoms associated with specific diagnostic categories and diagnostic agreement amongst clinicians and researchers (Flanagan et al., 2012).

However, researchers have since offered various critiques of the diagnosis of schizophrenia, both internationally and in South Africa, arguing that it requires levels of understanding that extend beyond the criteria of standard diagnostic systems and that a diagnosis based only on these symptoms limits the scope of treatment (Baumann, 2004; Boyle, 1999; Hirschfeld et al., 2005). Another author in the field elaborated on this critique by noting that the label of schizophrenia creates an artificial divide between people with “abnormal” functioning and people with “normal” functioning (Bentall, 2004). Similarly, Laing’s (1960) phenomenological approach to a diagnosis of schizophrenia aimed to highlight the lived experience of the person, instead of pathologising the individual. In this regard, Bentall, Jackson, and Pilgrim (1988) suggested abandoning the syndrome approach to the diagnosis of schizophrenia and studying psychotic symptoms instead. Chadwick, Birchwood, and Trowe (1996) agreed by arguing that this approach allows for the personal experience of psychosis to be taken into account.

Some clinicians and researchers therefore prefer to use the term “psychosis”, arguing that it can be used to cover a wide range of unusual perceptions and beliefs in patients presenting for the first time to mental health services without the stigmatising connotation of labelling it as a disorder (Wood, 2013). Others suggest stepping back entirely from medically-orientated concepts such as “schizophrenia” and “psychosis”, supporting individuals who form part of the recent Psychiatric Consumer/Service Users’ Movement and who have begun to reclaim terms such as “madness” in personal accounts of their diagnoses (Dillon & May, 2002; Russo, 2001).

Although contributions from various theorists and researchers in social, psychological, and physiological paradigms have provided a more comprehensive understanding of the diagnosis of schizophrenia and its associated symptoms, this diagnosis still seems to defy easy answers (Berzoff et al., 2011). In looking at the complexity of the development of the diagnosis of schizophrenia, informed by the medicalisation critique, the clinical picture and etiological considerations associated with this diagnosis are also relevant.

## **Clinical Picture**

In contemporary psychiatric diagnostic systems, the term schizophrenia is typically used to refer to a collection of illnesses; a syndrome that manifests in diverse symptomatology depending on a combination of external and organic factors (Berzoff et al., 2011). In the APA's (2013) DSM-5 classification system, people are diagnosed with schizophrenia if they manifest characteristic signs and symptoms of the illness for at least six months, with one month of "active phase symptoms" (i.e., two or more of the following: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, or negative symptoms such as diminished emotional expression, avolition, anhedonia, alogia and asociality). The term "psychosis" refers to a mental disorder in which there is partial or complete withdrawal from reality, most notably including the following two symptoms: (1) delusions as fixed beliefs that are not amenable to change, despite conflicting evidence; and (2) hallucinations as perception-like experiences that occur without an external stimulus (APA, 2013). It is important to note that the presence of psychotic symptoms does not necessarily mean that an individual is considered to be suffering from schizophrenia, because psychosis also refers to a range of symptoms that are included in other diagnostic categories (APA, 2013).

## **Etiological Considerations**

There exist a wide range of academic theories pertaining to the etiology of the development of symptoms associated with this diagnosis, with researchers being unable to agree upon the exact cause of symptoms (Berzoff et al., 2011). Geekie and Read (2009) distinguish between biological, evolutionary, neuropsychological, psychological, psychodynamic and psychoanalytic, communication and family, life event, sociological and anthropological, philosophical and existential, as well as spiritual, theories.

The start of the biomedical movement, or Decade of the Brain, gave rise to fields such as biological psychiatry and neurology (including works such as Bloom, 1993; Buchanan & Carpenter, 1994). While psychological approaches tend to employ understandings of normal human processes to make sense of unusual presentations as seen in the experience of psychosis (Geekie & Read, 2009), biological theories emphasise the biological mechanisms involved in the pathogenesis of a physical disease of the brain which can categorically be separated from "normal" human processes (Baumann, 2015; Cohen, 2008; Geekie & Read, 2009). The essence

of this biomedical position was articulated by former APA president Paul Applebaum, who noted that “our brains are biological organs by their very nature. Any [mental] disorder is in its essence a biological process” (as cited in Deacon, 2013, p. 848). Abnormal neurodevelopment (Carey, 2016; Fish & Kendler, 2005; O’Donnell, 2007) and neurodegenerative processes (McGlashan & Hoffman, 2000; Theberge, Williamson, & Aoyama, 2007) have for instance been widely studied as central to prolonged dysfunction as a result of symptoms associated with a diagnosis of schizophrenia.

In reaction to these biological theories of schizophrenia, a number of medications have been developed over the years to minimise the symptoms associated with this diagnosis (Taylor & Ng, 2012). This includes “typical” antipsychotics, mainly found to reduce positive symptoms of schizophrenia, but also shown to produce a range of extrapyramidal symptoms such as restlessness, muscle stiffness and changes in breathing and heart rate (Berzoff et al., 2011). The “atypical” antipsychotics were then developed to target both positive and negative symptoms with fewer side effects (Berzoff et al., 2011). However, metabolic side effects have been noticed and the rates of non-compliance to these medications are tremendous (Berzoff et al., 2011). For instance, a naturalistic follow-up study indicates that only 25% of first-episode schizophrenia patients comply with their antipsychotic medication consistently for the first year after starting treatment. This is problematic as non-compliance is one of the greatest predictors of relapse in schizophrenia (Khamker, 2015). Biological theories of severe mental illness have played a crucial role in informing theory and practice as well as greatly broadening contemporary understandings of a diagnosis of schizophrenia (Deacon, 2013). This has benefitted areas such as problem recognition, mobilising an effective response, and stigma reduction (Kirmayer et al., 2015). However, critiques surrounding the medicalisation of mental illness, including schizophrenia, have stimulated public and academic dialogue questioning the usefulness of the medical model (Andreasen, 2007).

### **The Subjective Experience of Mental Illness**

In reaction to the limitations of traditional scientific ways of making sense of the diagnosis of a mental illness, integrative models have been suggested that move away from the dichotomous thinking of “nature versus nurture” and allow for the exploration of the complex interplay between various factors in understanding and treating mental illnesses (Baumann, 2015; Berzoff et al., 2011). Alternative psychosocial models of illness and health have

questioned the assumptions of the dominant paradigm of the medical model, maintaining that the concepts of illness and health have great complexity (White, 2002). The biopsychosocial approach, for example, has allowed for conceptualisations of a diagnosis of schizophrenia in terms of psychosocial factors such as neglect and abuse (Joseph, 2004), trauma (see Chapter Five), urban living (Van Os, Hanssen, Bijl, & Vollebergh, 2001), poverty (Read, Mosher, & Bentall, 2004), racism (Karlsen & Nazroo, 2002), discrimination (Janssen, Hanssen, & Bak, 2003), as well as stigma and social marginalisation (Lysaker, Hunter, Strasburger, & Davis, 2005; McGrath et al., 2004; McKenzie & Shah, 2015; Mestdagh & Hansen, 2014; Read, Perry, Moskowitz, & Connolly, 2001).

Apart from researching psychosocial influences, clinicians, academics, patients and writers in fields inside and outside of social constructionism (including critical psychiatry, disability studies, illness and narrative, consumer/survivor/ex-patients rights activists, civil libertarian advocates, and more recently, medical humanities) agree that, while biomedical advances should be acknowledged, it is also crucial to respect the experiences and narratives of those diagnosed with severe mental illnesses (Cohen, 2008; Karp & Birk, 2013; Kirmayer et al., 2015; Kleinman, 1988b, 2015).

### **The Subjective Experience of the Diagnosis of Schizophrenia**

Attention to the subjective experience of specifically schizophrenia is deemed crucial as an addition to “objective” research into schizophrenia (Baumann, 2010; Davidson, 2003; De Wet, 2013; De Wet, Swartz, & Chiliza, 2015; Estroff, 1989, 2004; Geekie et al., 2012; Geekie & Read, 2009; Jenkins & Barrett, 2004; Robbins, 1993; Wood, 2013). The narratives of individuals diagnosed with schizophrenia are useful for three types of reasons: (1) ethical reasons, (2) the therapeutic impact of sharing narratives, and (3) changing dominant discourses.

Fulford and Hope (1993) claim that “understanding the patient’s actual experience is the basis of sound medical ethics” (p. 691). Other authors who put forward ethical arguments for studying the subjective experience of individuals diagnosed with schizophrenia, state that if people do not relate their own experiences in their own words, it can lead to the “silencing” of individual stories (Geekie & Read, 2009). This is worsened by the fact that the words of individuals with this diagnosis are often perceived as incoherent and meaningless (Estroff, 2004; Wood, 2013). Of this, Estroff (2004) says: “What is at stake here is authority and authenticity

concerning identity, definition, meaning and experience in schizophrenia - and ultimately what happens to and about people with schizophrenia” (p. 283).

Secondly, Wood (2013), in her review of narratives of people diagnosed with schizophrenia published in the *Schizophrenia Bulletin*, remarks that the narratives itself prove essential to the process of meaning-making and renewed self-understanding. This gives the narrator “the opportunity to renegotiate the meaning, sequence and connection between past and present life events and accept[ing] themselves and their personal histories” (Geekie et al., 2012, p. 9). This is crucial when taking into account phenomenological accounts of schizophrenia as a diagnosis which affects the person’s sense of self in the world, which no longer feels like their own (Kirmayer et al., 2015). Narrating a subjective experience then provides individuals with an opportunity to experience the contents of their story as belonging or relating to themselves and their world. May (2003), a clinical psychologist diagnosed with schizophrenia, argues not only for the therapeutic value of narrating your own story, but also that exposure to other people’s experiences of and recovery from mental illness, can serve therapeutic value in creating hope.

Thirdly, as only certain aspects of the experience are available to the person diagnosed with schizophrenia, attention to subjective experiences can help challenge and subvert simplistic or fixed assumptions typically found in dominant discourses (Hare-Mustin & Marecek, 1990). This third argument is particularly important for challenging the traditional notion that there is no hope for recovery after being diagnosed with schizophrenia (Ridgway, 2001). The presumed loss of self and loss of touch with reality in schizophrenia (Andreasen, 1984), has been replaced with a recognition of possibilities for recovery, along with the reemergence of the person from behind the diagnosis (Geekie & Read, 2009).

Currently, there are signs of a shift within the literature, with attention being given to the subjective experience of being diagnosed with schizophrenia and living with the associated symptoms (Hirschfeld et al., 2005). There thus is a growing number of published accounts of the subjective experience of individuals diagnosed with schizophrenia (Boydell, Stasiulis, Volpe, & Gladstone, 2010; De Wet, 2013; Read et al., 2015), including the life stories of such individuals (Hornstein, 2002; Saks, 2007). However, it is still rare for these first-hand accounts to be acknowledged or incorporated within the professional, scientific literature on schizophrenia (Geekie & Read, 2009). More generally, authors have increasingly argued for the use of narrative (Chase, 2005; Cohen, 2008; Holmes, 2000; Thomas & Longden, 2013) and other



qualitative approaches (such as phenomenological approaches) to the study of mental illness in psychiatry (Baumann, 2010; Brown & Lloyd, 2001; Kirmayer et al., 2015; Whitely & Crawford, 2005; Willig & Stainton-Rogers, 2008). In diverse fields such as traditional psychiatry, existential psychiatry, psychoanalysis, phenomenology, psychosocial rehabilitation and dialogical psychology, schizophrenia has been theorised differently - leading to alternative theoretical and empirical research.

**Theoretical research.** Since Kraepelin theorised that people diagnosed with schizophrenia have problematic experiences of subjectivity, much theoretical research has focused on alterations in the self-experience of people diagnosed with schizophrenia (Lysaker & Lysaker, 2010). Laing (1960), a popular theorist in the field of existential psychiatry, proposed that self-experience in schizophrenia involves feelings of alienation and terror, together with feelings of loss and incapacity (as mentioned by Boss, 1979). Some psychoanalysts, such as Freud, theorised that people are diagnosed with schizophrenia when they detach themselves from the outside world and refocus their psychotic energies on themselves, essentially trapped in a state of exclusive self-relation (Lysaker & Lysaker, 2010). Other psychoanalysts, such as Frosch (1983), argued that this causes a simultaneous desire for, and terror of, connection with others. More recently, from a psychosocial rehabilitative perspective, Davidson (2003) writes about the feelings of social alienation - a longing for connection, but a fear of rejection - and about feelings of being unable and unworthy to influence the course of their own lives. Phenomenological theorists, like Blankenberg (2001), not only write about feelings of anxiety and emptiness, but link the disordered psyches of people with this diagnosis to a breakdown in what he refers to as “common sense” during interactions between the self and the world.

**Empirical research.** In recent years, investigations into how people diagnosed with schizophrenia experience and understand their diagnosis and its associated symptoms have developed through the use of research methods that engage with subjective experiences. Davidson (1992) used a phenomenological qualitative approach in researching schizophrenia. In this conceptual framework, “people are viewed as purposefully engaged in meaningful life projects that extend over time” (Davidson, 1992, p. 4). His approach, as well as other more person-centred approaches, found that factors concerning the person, for example hope, courage,



a sense of self, and being an active agent in the process of recovery, are crucial in order for improvement to take place (Hirschfeld et al., 2005).

Geekie and Read (2009), in conducting first-episode psychosis research at an outpatient community mental health care centre in New Zealand, identified the following themes in individuals' descriptions of their lived experiences: storytelling and authoring, causes of psychosis, describing the experience, impact of the experience, responses to and coping with the experience, as well as spiritual and cultural issues. In a similar study, Larsen (2004) investigated the experience of clients of a Danish first-episode psychosis service. Like Geekie and Read, Larsen emphasises meaning-making as an active process, with individuals capable of demonstrating flexibility by relying on personal resources, such as spirituality. Corin, Thara, and Padmavati (2004), in their study of patients diagnosed with first-episode psychosis in India, also state that patients' search for significance and meaning, as well as spiritual concerns, were main themes. As such, Boydell et al. (2010), in their review of studies of first-episode psychosis, found that the majority of qualitative research present findings on complex individual and social processes such as achieving identity, acquiring perspectives, participating in activities, and developing relationships.

Patients diagnosed with first-episode psychosis describe the psychotic experience as interfering with how they perceive themselves; they feel distant from themselves, and are overcome by a frightening feeling of having lost themselves (Moller & Husby, 2000). They also describe an extreme preoccupation with their inner world - needing to analyse everything they are thinking (Moller & Husby, 2000). Stanghellini and Ballerini (2007) found that patients diagnosed with schizophrenia are mainly concerned with what is real and what is unreal, with phenomena normally seen as facts being questioned. They also found that persons with this diagnosis experience a loss of common sense and feel disconnected from shared realities with other people. Similarly, Hirschfeld et al. (2005), in their social constructionist study of young men's experiences and processes of making meaning of psychosis, found that their usual interactions with the outside world changed, with the men experiencing themselves as suspicious and insecure.

In these and other studies (such as Kilkku, Munnukka, & Lehtinen, 2003), the sense of a loss of control appears to be an important aspect of the psychotic experience. Michelle, Campbell, and Morrison (2007) compared the subjective experience of paranoia between

persons who sometimes have paranoid feelings without being diagnosed with a mental illness, and people diagnosed with a schizophrenia spectrum disorder. While participants from both groups reported having experienced unusual feelings or perceptions, the individuals diagnosed with a disorder reported having experienced what they hear or see as outside of themselves; outside of their control. On the other hand, the individuals without the diagnosis experienced having control over their thoughts, ideas and feelings. This feeling of having control in life seems to play a central role in recovering from psychosis, with hospital patients diagnosed with psychosis describing strategies to take control of hallucinations and becoming active agents in their lives as part of the recovery process (Roe & Lachman, 2005). In Deland, Karlsson, and Fatouros-Bergman's (2011) phenomenological analysis of the psychotic experience of individuals diagnosed with schizophrenia and postpartum psychosis in Sweden, they concluded that a psychotic experience is seen as a breach with normal, ordinary and rational life. This involves an estranged relationship with the self, others and the world. However, they argue that it cannot be said that a person is totally lost in this psychotic world, because of the subjective and personal experience of suffering that accompanies the psychotic experience.

As such, Kirmayer et al. (2015) state that, because the suffering that is associated with mental illness is tied to certain experiences and phenomenology that essentially emerge from active processes of perception, action, and interpretation, it is crucial to include agency, meaning-making and regaining a sense of control into models of mental illness. However, Wagner and King (2005) found that the existential need of finding meaning is an issue that is rarely adequately addressed in clinical settings in Brazil. Geekie and Read (2009) agree that clients often feel as if their subjective needs are being disregarded in mental health care services.

Clinical studies have incorporated similar reasoning to the above qualitative studies, into the treatment of psychotic experiences. Chadwick et al. (1996) explained that the theory and practice of cognitive behavioural therapy for psychosis highlights the concept of the self and brings the actual person with psychosis to the fore. More recently, British cognitive psychologists have been advocating for the involvement of psychologists in the field of psychosis; they suggest that hallucinations and delusions are understandable in terms of normal psychological processes (for instance Garety, 2001) and that cognitive therapy, combined with psychodynamic techniques, can be effective for psychosis (for example Garrett & Turkington, 2011, elaborated on in Chapter Five). Other psychological approaches have also proven to be

effective for treating or managing people with a diagnosis of schizophrenia (Read et al., 2004). For instance, results from a landmark clinical study conducted in America concluded that patients diagnosed with schizophrenia who received programs which emphasise individual therapy, family support, and patients' roles in their own care, made better progress in recovery than patients who exclusively received drug-focused care (Carey, 2011, 2015a, 2015b).

**South African research.** Cultural psychiatry research as well as psychological and medical anthropology, have explored how mental illness is socially constructed in specific contexts (Kirmayer et al., 2015). For example, Field (1960, 1968), a psychiatrist and anthropologist who studied mental illness in Ghana, identified individuals labelled as “chronic psychotics”. These individuals were thought to be “too mad” to be treated by traditional healers and were later deemed more fit for the colonial asylums, described to be “a place for the demented and dangerous, people who were burdens and created troubles for family and society” (Bell, 1991, p. 16; see Swartz, 2015). Numerous African studies included racist notions of the primitive “native mind”, with psychiatrists wanting to confirm the presumed etiology of schizophrenia as a disorder caused by civilisation (Read et al., 2015). However, this became the foundation of investigations into how culture and social context shape the ways in which people experience, express and cope with suffering from an illness (Kirmayer et al., 2015). While certain studies illustrate a similarity between psychotic processes across diverse cultures (Kirmayer et al., 2015), numerous arguments have been posited for an attention to culture and context in psychiatric research, theory and practice - not only in response to human diversity, but also in response to recent advances in the understanding of the brain's plasticity, attunement to social interaction, and adaptability (Kirmayer et al., 2015).

One local example would be Asmal et al.'s (2011) literature review on implementing family therapy in South Africa. This study advocates that cultural ideologies should be taken into consideration as it influences families' beliefs of schizophrenia, expected expressed emotions and levels of stigma. Similarly, Mosotho (2011) argues that cultural differences play a role in shaping delusions and hallucinations as well as in understanding the expression of somatic symptoms of schizophrenia in a group of Sesotho speakers from the Mangaung Township in Bloemfontein. As such, the authors of *Schizophrenia, Culture and Subjectivity* posit that “culture is critical in nearly every aspect of schizophrenic illness experience” (Jenkins & Barrett, 2004, p. 4). These and other authors also argue that international studies on the subjective experience of

schizophrenia might not be relevant to individuals in developing countries, not capturing the complexities of the experience of schizophrenia in the developing world (Baumann, 2010; De Wet, 2013; K & Duncan, 2006; Read et al., 2015). Kleinman (1988b) has specifically criticised many cross-cultural psychiatric studies – he argues for actively listening to patients’ narratives in rebuilding identities, instead of imposing diagnostic boundaries on individuals from developing countries and, in doing this, excluding symptoms that are influenced by cultural aspects.

Empirical and theoretical studies that present findings pertaining to individuals diagnosed with schizophrenia in South Africa, cover aspects such as: the experience of mental health services, interventions, information and treatment (Asmal et al., 2011; Brooke-Sumner et al., 2015; Kotze, Van Delft, & Roos, 2010; Lund et al., 2010; Motlana et al., 2004; Zubi & Connolly, 2013); cultural differences (Ensink, Robertson, Ben-Arie, Hodson, & Tredoux, 1998; Mosotho et al., 2011; Sorsdahl, Flisher, Wilson, & Stein, 2010); trauma (Burns, Jhazbhay, Esterhuizen, & Emsley, 2011); recovery (De Wet, 2013; De Wet et al., 2015); neurobiological abnormalities (Chiliza, 2015); intersubjectivity (Bradfield & Knight, 2008); and aspects of the community such as stigma and family support (Bishop, 2014; Botha, Koen, & Niehaus, 2006; Molefi, 2009). Of the studies that present findings concerning schizophrenia in a South African context, a large portion implement standardised, quantitative methodology (Read et al., 2015). It appears that there is a paucity of literature which investigates the subjective experiences of individuals diagnosed with schizophrenia in the South African context and also specifically in the Western Cape. Below, I report on some of the findings of qualitative studies with individuals diagnosed with schizophrenia in South Africa.

Recently, first-person accounts of living with a diagnosis of schizophrenia in South Africa have been related in both popular and academic publications by authors such as Charlene Sunkel (2016), Harriet Christou (2013), Siyabulela K (K & Duncan, 2006) and Henriëtte van Rooy (Van Zyl, 2016). These and other first-person accounts illustrate processes of active meaning-making as reflected in the above mentioned international studies on the subjective experience of schizophrenia.

Existing subjective research in South Africa further indicates that individuals struggle to define schizophrenia, with Sotho names such as “bohafi” (madness) and “boloi” (bewitchment) being used (Motlana et al., 2004). Motlana et al. (2004) indicate that the outpatients in their qualitative study perceive schizophrenia as an illness caused by both medical as well as social

causes. Asmal et al. (2011) add that, in their literature review, the blame of mental illness is often placed outside the patient, with spirit possession seen as playing a role in containing inner conflict in vulnerable or powerless people. The concept of “ukuthwasa” is commonly used to describe the emotional turmoil of a person on a path to becoming a traditional healer (Swartz, 1998) - deserving of support, special treatment and sympathy. In situations where the individual is unable to complete training to become an indigenous healer, a retrospective diagnosis of “ukuphambana” (madness) can be given (Swartz, 1998). The themes of jealousy, bewitchment, guilt and ancestral calling are common explanatory models for schizophrenia in Africa, with patients and families often supporting treatment and hospital admission as symptomatic control, together with further intervention from an indigenous healer (Mbana et al., 2002). This illustrates an existing dichotomy between the traditional healing model and the medical model (Motlana et al., 2004).

Kotze et al. (2010), drawing attention to the voiced needs of outpatients diagnosed with schizophrenia in Pretoria, highlight a miscommunication between patients and mental health professionals about what constitutes their diagnosis. The participants in their study specifically call for effective dissemination of information as well as improved support in managing the consequences of a diagnosis of schizophrenia. Additionally, Zubi and Connolly (2013) explore individuals’ recollected experiences of first-time admission to a South African psychiatric hospital after a diagnosis of acute psychosis in schizophrenia. These individuals report distressing, frightening, traumatic, and emotionally painful experiences. This study concludes that this, together with the individuals’ isolating and stigmatising diagnosis, can have a long-term implication on recovery and reintegration into society (Zubi & Connolly, 2013).

In spite of feeling misunderstood by mental health professionals, patients seem to yearn for respect, empathy and a chance to prove their worth, because of feeling rejected and persecuted at times by members of the community. Mbana (2002) agrees that stigma is indeed pervasive, with relatives of Xhosa-speaking patients diagnosed with schizophrenia stigmatising them as dirty and dangerous. A phenomenological case study focusing on the subtleties of the intersubjective experience of a woman diagnosed with schizophrenia, reflects the sense of isolation, caution in relationships and diminished sense of self-worth that can be experienced as part of a diagnosis of schizophrenia (Bradfield & Knight, 2008). She struggled to communicate herself to others and felt misunderstood and unheard by others (Bradfield & Knight, 2008).

Lastly, in a study similar to the current study, De Wet et al. (2015) implemented a phenomenological approach to analysing the subjective experiences of recovery in a sample of patients diagnosed with first-episode psychosis in schizophrenia in Cape Town, South Africa. Their findings highlight the importance of support, having to care for another, spirituality, and re-discovery of personal abilities in contributing towards a sense of agency in the process of recovery. Stigma is again noted as a pervasive barrier to recovery.

In summary, despite the medicalisation critique of mental illness that has influenced the history of the diagnosis of schizophrenia, numerous scholars are still critical of the existing research on schizophrenia. These scholars claim that, despite the proliferation in quantitative studies, it is unclear to what extent current research has achieved a sophisticated and comprehensive understanding of the emotional distress of individuals diagnosed with schizophrenia and how they make meaning of their distress. The relevance of diagnostic categories such as schizophrenia, specifically in the developing world, has also been questioned. On recognising the suffering behind this diagnosis, new conceptualisations of a diagnosis of schizophrenia have suggested the importance of also incorporating a psychological and subjective perspective on the pathogenesis of schizophrenia, especially in developing countries, while acknowledging the biological underpinnings. In order to do this, I implement a qualitative research methodology, informed by a social constructionist theoretical framework.

## CHAPTER FOUR: METHODOLOGY

In Chapter Two, the social constructionist theoretical framework that informed the current study was explored. In Chapter Three, a brief literature review concerned with the diagnosis of schizophrenia was discussed. A detailed description of the methods employed in the current study follows. I start this chapter with a description of the qualitative research and multiple case study design of this study. This is followed by issues pertaining to collecting data from the sample of this study. Thereafter, I discuss the data analysis methods that were implemented. This chapter ends with an exploration of issues pertaining to validity, reflexivity and ethical considerations.

### Methodology

#### Research Aim and Objectives

The previous chapters have argued for the importance of also studying how individuals diagnosed with schizophrenia experience and understand their diagnosis and the symptoms associated with the diagnosis, especially in developing countries. This study therefore set out to explore how individuals from the Western Cape subjectively experienced and made sense of a diagnosis of schizophrenia and the symptoms associated with this diagnosis. This aim was engendered by a social constructionist theoretical perspective and qualitative research methodology, including a semi-structured interview schedule and social constructionist grounded theory method of data analysis.

#### Research Design

**Qualitative research.** This study, being informed by social constructionism, is qualitative and inductive in nature. According to Willig (2013), qualitative research methodologies are firstly concerned with how individuals experience events and make sense of the world (Henwood & Pigeon, 2003). It therefore focuses on exploring some aspect of individuals' experiences and reflecting upon it in a way that leads to a deeper and more complex view of personal subjectivity that is often overlooked in quantitative research methodologies (De Vos, Strydom, Fouche, & Delport, 2005; Terre Blanche et al., 2006). Additionally, qualitative research highlights how things work in different contexts (Mason, 2002). More specifically, a qualitative study can be inductive in nature, with researchers beginning with specific



observations and allowing categories of analysis and the generation of theory to materialise from the data itself (Willig, 2013). This is summarised in a broad definition of qualitative research by Denzin and Lincoln (as cited in Mertens, 1998):

Qualitative research is multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials - case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts - that describe routine and problematic moments and meanings in individuals' lives (p. 160).

A qualitative, inductive research design was the clear methodology of choice for studying the complexity of the subjective experience of a diagnosis of schizophrenia - concerned as it is with exploring the texture and weave of everyday life; the subjective understandings and experiences of participants in their contexts; the way in which social processes and discourses work; and the significance of the meanings that are generated (Mason, 2002). Moreover, the chosen qualitative research approach is in congruence with the semi-structured interview schedule and the social constructionist grounded theory data analysis technique (as discussed below). Additionally, qualitative research not only has the potential to contribute towards a greater understanding of a diagnosis such as schizophrenia, but also has the potential to make the participants feel heard and empowered (Davidson, 2003; De Wet, 2013).

**Case study.** This study can also be regarded as utilising a case study design. A case study design is defined as an “intense focus on a single phenomenon within its real-life context” (Yin, 1999, p. 1211), highlighting the significance of the role that context plays in the case study. Despite the fact that qualitative research has been regarded as being problematic because of limited generalisation and problems with validity, case studies are commonly used to rather provide a thorough, rich, detailed and in-depth insight into a single example of a phenomenon (Flyvberg, 2006; Terre Blanche et al., 2006) - in this case, the subjective experience of a group of South African individuals diagnosed with schizophrenia.



With a qualitative case study design, it is argued that human beings are complex, multi-faceted, situated, in process and under construction. The experiences of individuals are therefore analysed by considering and providing thick descriptions of multiple factors such as subjectivity, context, history, intersubjectivity, material details of lives, language, discourse and the unconscious. More specifically, a multiple case study design (see Rosenthal & Rosnow, 2008) was employed, by which an analysis of the first case leads the researcher to new research questions, which may change with the addition of each new case (Willig, 2013). This kind of design is chosen above a single case study design, as it does not only allow the researcher to explore similarities between cases, but also differences, and facilitates the generation of theory (Charmaz, 2006, 2008; De Vos et al., 2005; Willig, 2013).

### **Research Setting**

**Stikland Hospital.** The group of participants for this study was recruited from the Schizophrenia Research Unit located on the Stikland Hospital premises. Stikland Hospital is a government-funded psychiatric hospital situated in Bellville in the Northern suburbs of Cape Town, Western Cape, South Africa. This hospital provides in- and outpatient mental health care services as well as support groups and projects in multi-professional teams (including psychiatrists, psychologists, social workers, occupational therapists, pharmacists, and nursing personnel) (“Stikland Hospital,” n.d.). Stikland Hospital caters for a catchment area of approximately 1,500,000 people, consisting of two regions: one in the Cape Town metropolis and one in the rural regions of the West Coast and the Winelands (“Stikland Hospital,” n.d.). In addition to service-constraints such as limited resources, the Cape Town urban population is generally marked by economic deprivation and high levels of poverty, crime and violence (Lund et al., 2010).

**Schizophrenia Research Unit.** The Schizophrenia Research Unit of the Department of Psychiatry in the Faculty of Medicine and Health Sciences at Stellenbosch University is located on the Stikland Hospital premises. A multi-disciplinary team (consisting of psychiatrists, psychologists, nurses and researchers) working in the Research Unit conducts research into schizophrenia, particularly the early outcomes of psychosis. The current research projects of the Research Unit mainly focus on clinical, pharmacological, cognitive, neuroimaging and pharmacogenetic aspects of the illness. The Unit is for instance responsible for working with the

schizophrenia cohort database of the Shared Roots research project - a project led by the Department of Psychiatry at Stellenbosch University ("Schizophrenia Research Unit," n.d.). This Shared Roots research project (Understanding the Shared Roots of Neuropsychiatric Disorders and Modifiable Risk Factors for Cardiovascular Disease) aims to interrogate genomic, neural, cellular and environmental signatures that are common to cardiovascular risk as well as the three neuropsychiatric disorders under investigation, namely: Parkinson's disease, post-traumatic stress disorder as well as schizophrenia ("Schizophrenia Research Unit," n.d.).

## **Participants**

**Sampling and recruitment.** The current study can be considered to have made use of convenience sampling, as participants from the target population were selected based on their willingness and availability to participate (Bless, Higson-Smith, & Sithole, 2001). This was acceptable, as the aim of this study was not to make generalisations (Bless et al., 2001) of the experience of schizophrenia to the wider population of individuals in South Africa, but rather to investigate the subjective experiences of a diagnosis of schizophrenia in this particular group of people. All participants were recruited through the Schizophrenia Research Unit on the Stikland Hospital premises. Participants were either attending there as part of the Shared Roots research project at the time of the interviews or had attended there in the past as part of another research project. The primary investigators of the Shared Roots research project granted me permission to access the schizophrenia cohort database of the Shared Roots project and approach and contact patients diagnosed with schizophrenia through the Shared Roots study.

After the Shared Roots project study nurse provided me with a list of patients and their contact details from the schizophrenia cohort database, participants were recruited to participate in this study by randomly selecting patients from the list according to the inclusion and exclusion criteria. The inclusion criteria for participants for the current study were: (1) Male or female, in- or out-patients, aged 18 years or older; (2) with a diagnosis of schizophrenia; (3) screened by a mental health professional as being able to provide written, informed consent to participate; and (4) able to speak Afrikaans or English. Exclusion criteria were as follows: (1) Significant physical illness and/or mental retardation. Participants were subsequently telephoned and invited to participate (refer to Appendix A for an outline of how the study was presented to potential participants telephonically). Practical issues were considered in scheduling a meeting between the participant and me at the Schizophrenia Research Unit in order to explain the study,

request consent and, if they agreed, conduct the interview. All of the participants telephoned agreed to participate, with some even explicitly expressing a willingness to talk to someone in order to help others with the same problems as them. Recruitment continued until a sample of twelve participants was interviewed and data saturation of conceptual information was achieved. In qualitative research, a relatively small sample size such as this is appropriate, because of the focus on an in-depth understanding of a phenomenon, rather than generalisability and statistical validity of results (Reid, Flowers, & Larkin, 2005).

**Socio-demographic details.** A summary of the socio-demographic details of the participants can be found in Table 1 (p. 33). Interviews were conducted with twelve participants, of whom three were English-speaking, one isiXhosa-speaking with a second language of English, and eight were Afrikaans-speaking. The ages of participants varied between 26 and 50 years, with a mean age of 34 years. Out of the group of twelve participants, eight were male and four were female. Most of the participants (10) self-identified as Coloured<sup>2</sup>, whilst one participant self-identified as White and other participant as Black. Table 1 further indicates that nine of the participants were single. All of the participants completed primary school, with five participants completing Matric and three of them going on to tertiary education. The majority of the participants (9) were unemployed at the time of the interview. Participants were in different stages of their diagnosis, all either currently receiving or having received anti-psychotic medication.

---

<sup>2</sup> I am mindful of the fact that the use of racial categories, such as Coloured, White and African/Black is controversial in South African scholarship (Swartz, Gibson, Richters, & Gelman, 2002). However, such categories are socially constructed and carry important social meanings. As such, I believe that it is impossible to conduct a meaningful analysis of the findings within the context of post-apartheid South Africa without making reference to previous racial classifications, since these still inform existing power relations.

Table 1

*Study participants*

Pseudonym	Age	Gender	Home Language	Ethnicity	Relationship Status	Education	Employment Status	Income (p.m.)
DJ	36	Male	English	Coloured	Single	Technikon	Assistant	R 4 500
Leo	50	Male	Afrikaans	Coloured	Relationship	Primary school	Unemployed	R 1 500
Eugene	46	Male	Afrikaans	Coloured	Single	Matric	Unemployed	None
Lisa	32	Female	English	Coloured	Married	Technikon	Consultant	R 8 000
Power	28	Female	Afrikaans	Coloured	Single	Primary school	Unemployed	R 1 500
Boom Boom	27	Male	Afrikaans	Coloured	Single	Grade 10	Labourer	R 5 500
Rudy	30	Male	Afrikaans	White	Single	College	Unemployed	R 1 500
Nosi	27	Female	IsiXhosa	African	Relationship	Matric	Unemployed	R 1 500
Savanna	44	Female	Afrikaans	Coloured	Single	Grade 11	Unemployed	R 1 500
Kloeks	31	Male	Afrikaans	Coloured	Single	Grade 8	Unemployed	None
Jappie	28	Male	English	Coloured	Single	Grade 10	Unemployed	None
Pieter	26	Male	Afrikaans	Coloured	Single	Grade 11	Unemployed	R 1 500

**Data Collection Instrument and Procedure**

Data for the current study was collected by means of conducting individual, in-depth, open-ended, semi-structured interviews with the twelve participants (see Appendix C for the interview schedule). Semi-structured interviews are the most widely used data collection method in qualitative research and is in congruence with the social constructionist grounded theory data analysis technique implemented in this study (as discussed below) (Willig, 2013). According to Willig (2013), interviewing works specifically well with studies of people suffering from chronic illnesses, where detailed descriptions about a specific aspect of their lives are obtained. She suggests the use of a semi-structured interview schedule in order to negotiate rapport between the interviewer and participant by allowing the interviewer to maintain control of the interview, while the participant can speak freely and openly.

The interviews were conducted in a private, closed office at the Schizophrenia Research Unit located on the Stikland Hospital premises, where all the participants previously participated in a research project, at a time and date most suitable for the participant. Before and after each

interview, participants were provided with refreshments. Each of the twelve participants was interviewed once, lasting between 20 and 50 minutes. The interviews were conducted by myself in either Afrikaans or English, as I am able to speak and understand these two languages and as it was imperative that I grasp the essence of the experiences that each participant conveyed. This also gave the participants the freedom to express their experiences in a language that they were comfortable with.

The goal and objectives of the current study and the procedure of the interview were explained in detail to the participants before the start of the interview. After the informed consent form was explained to and read by the participant, as well as any questions answered, each participant was required to sign an informed consent form (see Appendix D for participant information leaflet and consent form). Consent forms were made available in both Afrikaans and English. Thereafter, participants were asked to complete a socio-demographic questionnaire consisting of a selection of close-ended questions (refer to Appendix B for the socio-demographic questionnaire). The aim of this questionnaire was to collect specific socio-demographic information to describe the sample, including for instance age, ethnicity, relationship status, income, education and members of household.

The open-ended, semi-structured interview schedule indicates the topics that were covered by means of the interview and provides an outline of the general style of interviewing. The aim of this open-ended, semi-structured design was to provide a degree of structure to the interviews without limiting the participants' sharing of their subjective experiences. Kirmayer et al. (2015) suggest implementing interpersonal, empathic and perceptual skills when assessing subjective experience as "a conversation which conveys a friendly-neutral, non-judgemental atmosphere, is supportive of the patient's spontaneity, and provides a space for narrative or even poetic verbalisations of experiential examples and their contexts" (p. 78). Following the guidelines of conducting open-ended interviews (refer to Willig & Stainton-Rogers, 2008) as well as the skills suggested by Kirmayer et al. (2015), I conducted the interviews in an open and informal manner in order to build rapport and maintain spontaneity with the participants. Confidentiality, privacy and an empathic attitude were implemented throughout the interview process, contributing to an open, safe, and trusting relationship. I attempted to ask as few questions as possible, while also striving to cover all the indicated topics. The order of the questions varied and all the questions were not necessarily asked. In this way, participants often

led the interviews into novel, unexpected areas. While this sometimes caused me to feel uncertain and out of control, it probably delivered richer data than might have been yielded by a more structured technique (Dukas, 2013). I practiced active listening during the interviews by reflecting, paraphrasing and summarising what participants were saying. I became immersed in listening and hearing (Fisher & Embree, 2000). While I was deeply involved in my attempts to enter and relate to the individuals' subjective worlds, I attempted to temporarily suspend my prior learning of the topic of schizophrenia and preconceived notions of how the interview should proceed.

For the interviews, I wanted the participants to relate their narratives in their own words, but used the basic structure of the history section of a clinical assessment interview (Morrison, 2014). The format of, and topics covered in, the interview were based on an interview schedule conducted with outpatients diagnosed with depression as part of the Women's Mental Health research project conducted by the Psychology Department at Stellenbosch University (see Lourens, 2014). Following Morrison's (2004) guidelines of a clinical assessment interview, the interview focused on exploring the individual's understanding of the present diagnosis and associated symptoms. What was meant by "schizophrenia" was purposefully not specified so as not to shape participants' understandings of this term. The interview also included questions aimed at determining the context in which the participant's problems developed (refer to McWilliams, 2011; Morrison, 2014; Sadock, Sadock, & Ruiz, 2014). In the words of Morrison (2004):

Health care professionals don't treat illnesses, they treat people... This requires learning all you can about family background and biographical data. The process not only will help you get to know your patients, but may reveal material that illuminates and extends your knowledge of the cause and context of mental disorder (p. 70).

The first participant who was recruited and who agreed to participate also served as the pilot interviewee. After this pilot interview was transcribed and coded, my supervisor and I agreed that the interview questions were clear and unambiguous and elicited rich, detailed data and thick descriptions regarding thoughts, feelings, actions, and context. After each interview, I wrote a process note of my personal experience, feelings and thoughts about the interview and

participant. These process notes were consulted during the social constructionist grounded theory analysis of the data.

## **Data Management**

After disclosing to the participants why the interviews were being recorded and in which manner these recordings will be used, all open-ended, semi-structured interviews were audiotaped and then transcribed verbatim according to transcription rules (as developed by my supervisor Prof. Lou-Marié Kruger, and based on the work of Gail Jefferson, as cited in Hutchby & Wooffitt, 2002). Extracts from the interviews were translated, when necessary, from Afrikaans to English by me.

In terms of the transcription process, Kvale (1996) suggests that researchers start with transcribing a pilot interview. He also suggests that, because of the constructive nature of transcripts, the taped material should be listened to for a second time after transcription, while following the written material. In terms of reliability, Charmaz (1995) advises that the researcher conducts and transcribes his/her own interviews in order to engage with the data from the start of the research process. In my study, I transcribed the pilot interview verbatim within two days after conducting the interview. This gave me a thorough understanding of the transcription process in order to proceed with the following interviews with more insight and skill. I then proceeded to transcribe the following interviews within a week of conducting the specific interview. I also transcribed the research interviews myself as well as listened to the participants' narratives for a second time after transcription. This provided me with a good overview of the data and ensured that I engaged with the data from the beginning of the analysis. It also enabled me to clarify unclear words or narratives as well as recall non-verbal communication such as silences, tone of voice, an emotional moment, or laughter. The transcription process proved fascinating for me as I recognised information that I missed during the actual interview process. It is still possible, however, that certain non-verbal information got lost during the transcription process.

Complexities involved in the translation process were also taken into account (see Painter, 2014). When transcriptions were already in English, I included the words verbatim (not correcting grammar, language use and word repetitions or neologisms). Where necessary, I translated the citations of the participants from Afrikaans to English so that their own stories can

be understood and appreciated by diverse readers. In the process of translating the citations from Afrikaans to English, it is possible that some of the meanings of idiomatic Afrikaans words were lost. In an attempt to provide some of these nuances to the reader, the data extracts in Chapter Five include square brackets to clarify the subject of speech and include parentheses to refer to nuances in non-verbal behaviour and language use. Certain idiomatic and descriptive Afrikaans words and phrases were included as it is unique to the participants' contexts.

The interview data and transcriptions were stored electronically on a private computer in a file that was protected by passwords which were securely stored. Hard copies of transcripts were stored in a locked cabinet. Only my supervisor and I had access to the data. In addition, the names and surnames of participants were not used in any of the data collected during the interviews. Participants were given pseudonyms that were linked to their data. These pseudonyms were used in the current document and will also be used in any future academic outputs, such as conferences and published articles.

## **Data Analysis**

**Social constructionist grounded theory.** When considering a data analysis approach most suitable for the qualitative research design, social constructionist theoretical framework and goal of this study, social constructionist grounded theory was deemed most appropriate. According to Charmaz (2006), grounded theory consists of a set of flexible, inductive procedures that use the data as a starting point with the goal of developing a theory through successive levels of data analysis and conceptual development. The basic strategies of grounded theory can be summarised as follows (Charmaz, 1995):

- Discovering and analysing psychological and social processes
- Simultaneous data collection and analysis phases
- Analysis leads to discovery and theory development
- Memo-writing is used to elaborate on categories as a crucial step between coding the data and writing the paper
- Theoretical sampling can be used to refine, elaborate and exhaust conceptual categories
- Systematic application of grounded theory analytic methods leads to more abstract analytic levels from the data



- Delay of in-depth literature review

In an attempt to adopt grounded theory guidelines, without the objectivist, positivist assumptions in some of the earlier formulations, Charmaz's (2006, 2008) constructionist version of grounded theory was applied in this study. This had implications on the selection of participants, data collection, the format and procedure of the interviews, transcription of interviews, and data analysis. In the words of Schwandt (as cited in Charmaz, 2000): "Constructivism assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretative understanding of subjects' meanings" (p. 150). Charmaz (2000), in arguing for the constructionist analysis of data, contends that researchers must aim to understand the assumptions and meanings underlying the data itself in order to make emerging categories consistent with studied life.

In social constructionist grounded theory specifically, the researcher is seen as co-constructing the responses of the participants by actively constructing the research questions, influencing the research process and shaping the interpretation of data (Charmaz, 2006). A social constructionist perspective guides the researcher to create categories of the participants' beliefs and actions by endeavouring to stay as close as possible to how the participants make meaning of their lived experiences whilst being aware to not merely categorise the data into pre-existing concepts. This ensures the development of new meanings that can be supplementary to well-known concepts in a discipline. Hyden (1997) stated that the story that is told also conveys something of the self-image that the participant wishes to express:

The stories people tell are important not only because they offer an unmatched window into subjective experience, but also because they are part of the image people have of themselves. These narrative self-representations exert enormous power. They shape how we conduct our lives, how we come to terms with pain, what we are able to appropriate of our own experience, and what we disown (p. 50).

There are a number of reasons why social constructionist grounded theory was chosen for the current study. Firstly, as grounded theory is an accepted and formal set of procedures that can be implemented by qualitative researchers, it encourages a rigorous and systematic analysis of data, whilst still allowing for creativity in the research process (Henwood & Pigeon, 2003).

Secondly, this method of data analysis is deemed to be consistent with the social constructionist theoretical framework as well as qualitative research methodology of the current study, as it facilitates the description of the construction of lived experiences of participants from their subjective point of view (Charmaz, 2006, 2008). Thirdly, this method of data analysis encouraged me to stay close to the studied worlds of the participants and to develop authentic theoretical concepts from the empirical material that not only synthesise and interpret, but also illustrate processual relationships. As such, social constructionist grounded theory is often useful in areas where limited research has been done (Charmaz, 2006). As there are significant gaps in the literature of the subjective experience of individuals diagnosed with schizophrenia in South Africa, social constructionist grounded theory allowed for the development of tentative theoretical explanations.

Following the social constructionist version of grounded theory, as described by Charmaz (2006, 2008), the data analysis process began with the analysis of specific experiences and led to the development of abstract conceptual categories constructed by me as the researcher during the interaction with the participants as well as with the data. Firstly, I performed open and descriptive line-by-line coding of the data. Coding in qualitative research is described as labelling, separating, compiling and organising data by the active and on-going construction of categories that emerge from interpreting the data (Charmaz, 2006). I used this to create initial order by using codes related to the general context, central participants and their roles, what is emphasised and what is ignored, as well as in-vivo and implicit codes. Thereafter during focused coding, I selected a limited number of these line-by-line codes based on the language used by participants or what I was interested in studying and applied this to the large amount of data. This aided the process of going back to the data and re-shifting it in relation to newly constructed categories and sub-categories. During this stage, I also consulted the literature as a source of questions and comparisons in order to expand and clarify codes. Next, during memo writing, I made written elaborations of ideas about the data and coded categories, such as processes, assumptions, and actions incorporated under each code as well as to define relationships between different types of categories. Lastly, I developed a theoretical conceptual analysis of the data by comparing the theoretical conceptualisation with existing relevant literature in the field of schizophrenia. In this regard, Charmaz (1995) suggests that the researcher should provide enough raw data in the written analysis to enable the readers to see the relationship between the

data and the analysis as well as the theoretical relationships. She also encourages the use of simple language and straight-forward ideas in order to make theory understandable and readable. Willig (2013) also advises that since this type of analysis aims to develop new and contextualised theories, researchers must maintain a certain distance from the existing literature by doing their own analytic work that builds on interpretations of the data and thereafter comparing these analyses with existing theory and literature. In this study, a brief review of the literature on the diagnosis of schizophrenia is presented in Chapter Three, where after I consulted the relevant empirical literature in Chapter Five. Throughout the study, I continuously revisited and read the data interpretatively and reflexively, rather than literally and superficially.

**Relational psychoanalysis and discursive psychology.** Data was analysed with the use of social constructionist grounded theory, with interpretations informed by relational psychoanalysis and discursive psychology. Following Frosh (1999, 2006), the analytical lens included paying close attention to detail and to social theory (typically associated with discursive psychology), as well as to individual biography and emotional subtexts (typically the terrain of psychoanalysis). Butler (as cited in Huffer, 2009) refers to a “Foucaultian perspective within psychoanalysis” (p. 170). Frosh and Saville Young highlight “the potential richness of results” (Frosh, Phoenix, & Pattman, 2000, p. 227) when such a research approach is used and explains this approach as follows:

Using psychoanalysis in qualitative studies involves conceptualizing individuals as embedded in social and cultural contexts with socially acceptable and powerful ways of being, but also as individually orientated to these contexts, uniquely invested in discourses in different ways influenced by conscious and unconscious wishes. Such an approach requires thinking about narratives as dynamic processes mediated by, but not reducible to, personal biographies, relational events, linguistic repertoires and subjective experiences (Frosh & Saville Young, 2008, p. 125).

In other words, while the principles of social constructionist grounded theory were adhered to during data analysis, I also paid attention to unconscious processes and underlying discourses - which also became strategies during the coding process.

## Processes of Validation

Critics often question the validity and reliability of qualitative research findings as opposed to quantitative results, such as questioning the limitations of interpretations of the data. Golafshani (2003) postulates that the terms reliability and validity should be considered for a redefinition in order to render them applicable to qualitative studies. Firstly, as reliability is traditionally interpreted as consistency, or the extent to which the measure produces the same results when utilised multiple times under similar conditions, qualitative researchers are less concerned with reliability (Willig, 2013). Instead of aiming to measure a specific attribute in a large number of people, qualitative researchers rather focus on reinterpreting the findings from a different angle or exploring the same issues in-depth or in different contexts. Secondly, Willig (2013) defines validity as the degree to which the research describes, explains or measures what it is aimed to describe, explain or measure. Janesick (2000) notes that validity in qualitative research has more to do with whether or not the explanation fits the description in a way that is trustworthy, rather than establishing the “truth”.

Yardley (2008) suggests four key dimensions against which the validity and quality in qualitative research can be assessed and that were constantly kept in mind throughout this study, namely: (1) sensitivity to context, (2) commitment and rigour, (3) transparency and coherence, and (4) impact and importance.

According to Yardley (2000), there are multiple ways to establish sensitivity to context, including being considerate to the socio-cultural area of the study, to the participants involved, and also to the relevant theoretical literature. The theoretical and empirical context within which this study took place has been delineated in Chapters Two and Three. Also, in the social constructionist perspective, sensitivity to context is required in all the stages of the research process, particularly in dealing with participants and analysing the data. In an attempt to avoid decontextualizing data as grounded theory has been accused of, the application of social constructionist grounded theory focused on taking extensive verbatim quotes from the raw transcribed data, together with socio-demographic information, to serve as support of selected categories (Morrow, 2005).

Commitment and rigour can be demonstrated by prolonged engagement with the research topic, complete immersion in the data, and being meticulous when engaging in data analysis (Yardley, 2000). According to Davidson (2003), rich narrative and descriptive detail vouch for

the robustness and rigour of the study, because it allows for contradictory and alternative meanings. This implies looking for data that do not fit in with the already identified categories and in this way ensuring the reader that all the relevant data have been attended to (Yardley, 2008). As an attempt towards prolonged engagement in the field, I also formed part of the Schizophrenia Research Unit over a long-term period by attending monthly meetings.

Thirdly, transparency speaks to the clarity of the description of the stages in the research process, while coherence refers to the presentation of a sound analytic report (Smith, Flowers, & Larkin, 2009). This was attended to by aiming to follow a clear, visible, and systematic research process as far as possible (Patton, 2002), as discussed in this chapter. Further, the results and discussion of this thesis aim to combine an analysis of textual material that is rigorous and cautious by employing psychoanalytic and discursive concepts, but grounding it in focused ways of gathering personal biographical data and clearly observable contextual moves in interpretation (Frosh & Saville Young, 2008).

Lastly, and in terms of impact and importance, Smith et al. (2009) suggest that the validity of a qualitative research document “lies in whether it tells the reader something interesting, important or useful” (p. 183). I tried to produce “valid” and “reliable” data by carefully describing the research context and considering each of the study participants as an individual person who had to overcome and continue to face significant life challenges. One of my primary goals was to listen carefully and then give voice to individuals’ experiences and insights. The resulting analyses were built directly upon verbatim quotes, and were also revised regularly and checked during supervision with my research supervisor to ensure that the analyses did not stray far from the raw data itself. It is hoped that this thesis will offer, in Smith et al.’s (2009) words, “something interesting, important or useful” (p. 183).

### **Researcher Reflexivity**

While qualitative researchers differ in the importance they place on reflexivity in their research, reflexivity refers to an awareness from researchers regarding their influence on the construction of meanings throughout the research process and therefore an acknowledgement that researchers cannot remain “outside” of their own research (Willig, 2013). As mentioned before, the social constructionist theoretical framework of this study acknowledges that knowledge is negotiated and invented - or constructed - out of assumptions and ideas made available through the interpersonal and social context (Frosh & Saville Young, 2008). As such,

this framework acknowledges that the researcher forms part of the research situation, the discursive context and the phenomenon under study (Willig & Stainton-Rogers, 2008). Instead of viewing subjectivity as a problem, as in conventional research, Parker (2005) comments:

Subjectivity is viewed by psychoanalysis, as with much qualitative research, not as a problem, but as a resource (and topic). To draw upon one's own subjectivity in the research process does not mean that one is being "objective", but that one actually comes closer to the truer account. In psychoanalytic terms, the "investment" the researcher has in the material they are studying plays a major role in the interest that will eventually accrue from the research (p. 117).

Mauthner and Doucet (2003) suggest that reflexivity should include disclosing the social position of the researcher, his/her theoretical perspective(s), emotional responses to participants (as described in Chapter Five), the epistemological assumptions that inform his/her research, as well as detailed descriptions of the research methodology employed. It is also advised that researchers explore the personal relevance of their choice of topic, mostly write in the first-person style, and disclose relevant background information about themselves. The reflexive researcher should at all times remain conscious of the inherent power-relations that are at play in knowledge production - especially when research participants are drawn from vulnerable population groups. I have attempted to incorporate these elements throughout this thesis.

My identity (a white woman in my early twenties who grew up in a middle-class, urban community in the Western Cape and is currently studying a Masters in Psychology degree), together with my personal values, beliefs and life experiences, informed the study and the interpretations in various ways. Although it is said that a declaration of relatively explicit aspects of researchers' personas will never be complete enough to understand exactly what their contribution to the research might be (Frosh & Saville Young, 2008), the activity of reflexivity challenged me to engage in a continuous conversation about what I am doing, why I am doing it, how I am doing it, what I am finding out and what I am doing with what I am finding out.

If I think about why I am writing about Power and Rudy, or any of these individuals, I think of how I long to be useful. It is possible that this longing "to be of use" was tied to underlying emotions such as shame, guilt, pity, fear, complex theoretical imperatives, or even a

sense of identification with or curiosity about the person who suffers from this mysterious illness.

In terms of “how I am doing it”, I specifically became aware of and tried to minimise a possible power imbalance with the predominantly low-income, coloured, Afrikaans- and English-speaking patients suffering from schizophrenia - both within the research encounter, in the health care setting in which the interviews took place (some participants insisted on calling me doctor), and in the wider social context. Although some power differentials were unavoidable, I tried to remain aware of “whose words were privileged” (Madriz, Denzin, & Lincoln, 2000, p. 842) in the research process and I aimed to conduct the research in collaboration with the participants, rather than “on them or about them” (Greenwood & Levin, 1998, p. 3). For instance, I made a point of sitting at the same side of the table as participants. As the interview progressed and my familiarity with the participant increased, I adapted the language and terms that I used (refraining from labelling their experiences as “schizophrenic” or as symptoms of a “mental illness” and using simple, clear language), in order to put the participants at ease, build rapport and encourage them to feel heard and understood.

However, for me, this thesis raised a central question of which voice or voices researchers should use as they interpret and represent those whom they study (Chase, 2005). Estroff (2004) raises concerns regarding issues about the professional dominance of knowledge production and reproduction. This refers to the following line of thinking: if researchers and clinicians do not know what living with schizophrenia is like, and therefore lack knowledge to sufficiently understand or provide effective treatment, it challenges their authority to write about and dictate treatment for schizophrenia. On the other hand, clinicians/scholars can argue that, as patients often do not want to acknowledge, or not have sufficient insight, into the fact that they are diagnosed with a psychiatric illness, clinicians/scholars are responsible for studying these phenomena. Similarly, some researchers argue that “making sense” of findings by turning messy, confusing data into something logical and coherent may not reflect the nature and quality of human experience that are always and necessarily fragmentary and contradictory (Willig, 2013). This can specifically be applied to accounts of psychotic experience that impose coherence by narrative smoothing - causing a tidy version of a once perplexing, confusing, terrifying and chaotic story. But then, what do we/I do?



In the words of Kvale (1996): “Holding attentively to what emerges without irritably seeking to order and understand it, and simply encouraging participants to speak on or around the topic under study, is itself quite a radical move for researchers and can pay dividends in terms of the quality of narrative data that is produced” (p. 196). Without “irritably seeking order”, in contrast to my personality that often craves order and coherence, I adopted Estroff (2004)’s suggestion in expanding schizophrenia paradigms to welcome, acknowledge and include new understandings, new voices, contradictions, paradoxes and complications.

In thinking about “what I am doing with what I am finding out”, the challenge for me was to show that my engagements with these individuals can serve as useful knowledge. The point of this research is then not to search for the “truth”, but to undertake to know how, and up to what limit, it would be possible to think differently in representing the voices of the participants. It is hoped that this research will also be applicable outside of academia and affect social change in the lives of the people who are written about here.

### **Ethical Considerations**

Ethical clearance for the current study was obtained from the Health Research Ethics Committee (HREC) of Stellenbosch University with reference number S16/07/131 (refer to Appendix E for the approval notice). It follows then that this study was conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council Ethical Guidelines for Research. The following general and specific ethical considerations were implemented for the protection of the participants, as well as the researcher.

**General ethical considerations.** Preceding the interviews, I thoroughly explained the objectives of the study as well as the research procedure to the participants as per the informed consent form (see Appendix D for participant information leaflet and consent form). These forms were meant to protect the participants’ as well as the researcher’s rights and ensure transparency of the research procedure (De Vos et al., 2005). The informed consent forms highlight the following issues:

- The credentials of the supervisor and researcher
- The nature and goal of the research study



- Explanation of the interview procedure and participants' responsibilities in the study
- Potential benefits associated with participation
- Potential risks associated with participation
- Data management techniques
- Voluntary participation
- Participants' right to discontinue participation at any stage of the interview for any reason
- Decisions to withdraw from the study will not affect the participation in other projects at the Schizophrenia Research Unit
- Confidentiality and anonymity measures taken to ensure protection of participants' identities (from data collection to dissemination of information)
- That the researcher did not have access to participants' medical or personal records, outside of their diagnoses
- The availability of supportive resources should the participant express the need to be referred

After the above mentioned information was conveyed in clear language to the participants, all the questions regarding participation were answered. I reiterated that participation was voluntary and that they were free to withdraw at any point during the study without adverse consequences. If they agreed to participate, participants were asked to sign the informed consent forms. Consent forms were made available in both Afrikaans and English and participants were given a copy to take with them. After signing the consent forms, participants were again asked if they had any questions and specifically reminded of voluntary participation, free withdrawal, confidentiality, and anonymity. They were assured that I will be the only person listening to the recordings and that the transcriptions, without any identifying information, will only be made available to my research supervisor. No compensation was paid to the participants, except for contributing towards their travelling expenses to and from the Schizophrenia Research Unit.

**Specific ethical considerations.** As the interviews simulated a clinical interview, I received extensive training in interview skills as well as supervision from my supervisor, Prof. Lou-Marié Kruger, a registered clinical psychologist who has trained clinical psychology and qualitative research students at Stellenbosch University. Throughout the interviews, I carefully

monitored the mood and mental status of the participants. Although it was planned that the interview would be discontinued or the date of the interview rescheduled at visible signs of decomposition or distress, this was not necessary. Some of the participants became emotional, restless or lost their concentration during the interviews. At this point, I gave them the option to take a break or discontinue the interview. All the participants decided to continue with the interview after taking a smoke or coffee break.

It was also made clear that participants were free to decline to talk about issues during the interview, given the sensitive nature of the material that was discussed. I highlighted the contact details of my research supervisor at Stellenbosch University, as well as the contact details of the Welgevallen Psychological Clinic in Stellenbosch, in case there are any questions or if the participant feels that she or he might need help during a later stage. Fortunately, it was not necessary to call on such support.

Participants were also asked at the end of the interview whether they would like to have feedback about this particular study. I told those who agreed that I will provide them with individual, telephonic feedback once my research project is completed and when it is most convenient for them. Further dissemination of results will be academic: results will be reported in academic journals and at academic conferences. Because of my commitment to popularise important research findings, I will also make myself available to write for popular publications and speak in public forums such as support groups. In all instances of dissemination of results, the greatest care will be taken to ensure that individual participants are not identifiable. While care has been taken to maintain participant confidentiality, writing about participants, patients or clients always remains complex and problematic (for discussions on the complexities of writing about patients, refer to Kantrowitz, 2006; Swartz, 2012).

In this chapter, I discussed and explained the qualitative research methodology of this study, informed by a social constructionist theoretical framework. I obtained the data through individual, open-ended, semi-structured interviews with twelve participants from the Western Cape, South Africa. I analysed this data by implementing social constructionist grounded theory, with interpretations informed by relational psychoanalysis and discursive psychology. This is presented and discussed in the next chapter. I also explored issues of validity, subjectivity and ethical considerations inherent to my study.

## CHAPTER FIVE: RESULTS AND DISCUSSION

### Introduction

According to social constructionist grounded theory, the processes of data analysis, reporting the results and developing a theory are interrelated processes (De Vos et al., 2005) and will thus be presented together in this thesis. After analysis of the data with the use of social constructionist grounded theory, with interpretations informed by relational psychoanalysis and social theory, I identified the following categories: historical selves, complex emotional worlds, medical discourse, and care. In an attempt to keep some of the complication of the data (Davidson, 2003), I quote extensively from the interviews in order to substantiate categories and to enable readers to see the evidence, but also to make participants' voices audible.

I start this chapter with brief biographies of the participants, focusing on socio-demographic details, my interpersonal experience with them and some salient features from their histories. This is followed by an account of how participants described their complex emotional worlds, including the following sub-categories: fear, anxiety, and paranoia; shame; anger and aggression; loneliness and isolation; and sadness. Next, there is a discursive reading of the transcribed texts where I pay close attention to the underlying discourse of the medical model. Sub-categories include: the abnormal person, the dysfunctional brain, medical intervention, the medicated body, and the diathesis-stress model. I then discuss the importance that the participants placed on being cared for by others and caring for others, usually experienced away from the medical environment and in the context of family. I end by discussing what this need for care means for humanising the treatment and management of individuals diagnosed with schizophrenia in a clinical setting.

### Results and Discussion

#### Historical Selves

**DJ.** DJ is a 36-year-old, English-speaking, coloured man of Muslim religion (refer to Table 1 for a summary of the socio-demographic details of the participants). He holds a diploma in electrical engineering, but finds working in the field stressful and dangerous. In search of employment, he relocated from the Eastern Cape, where he lived with his father, to the Western Cape. He now lives with his mother and brother. He is currently employed as an administrative

clerk and personal assistant, with an income of approximately R4500 per month. He mentions taking daily Risperdal antipsychotic medication.

When I met DJ, he was neatly-dressed and polite. He came across as shy, but high-functioning. While he mainly spoke (in articulate, focused terms) about how his health has improved and what insight he has gained on his road to “living with the illness”, “recovering” and “becoming healthy”, he also told stories of being abnormal, seclusive and being bullied - by his peers at school, his father, and his brother.

*DJ: Uhm, I, listen, my illness started when I was very young.*

*C: How young were you?*

*DJ: Like maybe like five or six years old. And then I stayed in the Eastern Cape, so I- when I was in primary school I never used to associate myself with other people, I always used to sit by myself and I was scared of the environment. And uhm at the same time there were bullies also, but now- yes- so I did well in school, but I struggled to concentrate as well, so it took me for a normal person to study like say five pages of notes, it took me like maybe like uhm a day, two days just to study. You know.*

*DJ: Uhm my father- my mother and father got divorced when I was seven years old. My mother came to Cape Town and my father stayed in the Eastern Cape. My father and brother- we call it the divorce problems- they took it out on me, because I was the youngest in the house. And then also he was like very offensive and abusive towards me. Like emotionally, when I was small. So yes that also added to the stress of also having schizophrenia also.*

*DJ: Uhm, he [brother]<sup>3</sup> like- I would say sibling rivalry or something. Like he start to instigate this scheme like, uhm yes, I am the oldest so you must do what I say and all of that stuff you know. So, yes, also like uhm picking on me sometimes, or say for example there's no socks and I am wearing his socks and he will say: listen, take off those socks it is my socks. So then you know like small things like you know. Yes. Even today- 'till today my brother still thinks yes he can push me around or whatever.*

DJ also recalled more recent events of being exploited by friends in his social group:

---

<sup>3</sup> Square brackets clarify the subject of speech.

*DJ: Then also when you are socialising you must be careful what friends you choose by the social group, because sometimes some people come to the social group just to draw you in, they say: listen, after we go- after we go from here we can maybe go do some drugs or something, you know. So you must be careful also.*

*C: Did that happen to you?*

*DJ: Yes, it happened to me, but I'm not gonna- I can't tell you where. But they said: okay uhm, listen quickly give me a five Rand man. Give me a ten Rand then you can come with us, then we can quickly go smoke dagga [marijuana].*

It is notable that the voices he heard also seemed to control him:

*DJ: But also uhm the taste in my mouth and the voices was like a nightmare. Yes it was like a nightmare, because you play them all the time the voices that tell you: listen, do this, or uhm don't walk there, that guy is gonna attack you, you know.*

*DJ: So that's- I had in the past, I was sitting in a train, in the third class, and a guy and his girlfriend was sitting there and then I heard a voice he told me: listen, uhm when you get out just get a rock and hit him and you'll see you'll feel better.*

**Leo.** Leo is a 50-year-old, Afrikaans-speaking, coloured man. He has no religious affiliation. He shares an informal house with his girlfriend, located in the backyard of the house where his mother, stepfather and brother live. He described his girlfriend as being supportive and understanding. Leo is divorced and has minimal contact with his daughters. He completed primary school, but is currently unemployed and receives monthly grant money (approximately R1500 per month). He mainly complained of sleep difficulties, a lack of appetite and grinding his teeth, for which he says he has been receiving injections and pills since 2007.

Leo came across as unresponsive and exhibited flat affect and poverty of speech, only responding to close-ended questions. When it came to his diagnosis of schizophrenia, he seemed indifferent and compliant - remarking that he just takes the medication without knowing why. I felt disconnected from him; unable to identify with him emotionally and to initiate a flow of conversation. However, when allowing for (often long, uncomfortable) silences, I was surprised by short bursts of personal disclosure. One of those times was when he mentioned his traumatic time in jail and being mistreated by his ex-wife, without him defending himself.

*Leo: I was in jail also at a time, two years. For indecent assault. It's- my wife put me in jail for my own son. They then- then found me guilty. I got 15 years. And then I appealed and got released after 2 years. Yes. Sometimes I dream about the jail.*

*C: What happens in those dreams?*

*Leo: What can happen there, the gangsters and that. The gangsters in the jail.*

*Leo: Yes, yes with- I told her [ex-wife] my parents' wish is for me not to take her back. Yes. Because she told the child to say that it is me who molested him. Yes but he also said his mother told him to say it is me. Then when he told that to the magistrate, he said: that is not the question that was put forward. Yes. They treated me like a dog. But it is also my fault, because I did not actually talk about- when they asked me why. My wife said it is me who is doing these things to her. Then I did not answer.*

**Eugene.** Eugene, a 46-year-old coloured man, is Afrikaans-speaking and self-identified as Christian. At the time of the interview, he was single and lived with his mother, father and two brothers. After completing secondary school, he talks of a career in the police force. He is currently unemployed and without income. He has been receiving anti-psychotic injections for almost six years.

Eugene was well-mannered, referring to me as “dame” (madam), and talkative, often apologising for talking too much. It soon became apparent that he exhibits delusional thinking and grandiosity, clearly resisting the diagnosis of schizophrenia for himself. As a result, I was intellectually curious, but felt emotionally detached towards him. The content of his delusions involved him feeling out of control and being mistreated by people who he refers to as “rubbish” and “pigs”.

*Eugene: Like that thing controls me, I- I sometimes- is it that he- throws me around (laughs)<sup>4</sup>, he throws me around. But...but I- like I also told Donald [researcher], they talk about schizophrenia, but like I just told Donald, like I also told Sister Pou there at the other place, they talk about schizophrenia, but according to me, according to me, it is not schizophrenia that I have, it is someone who is doing these things to me. Because the whole story is about my child, my daughter, and the whole story is about my money that*

---

<sup>4</sup> Parentheses refer to nuances in non-verbal behaviour and language use.

*they have and that they also don't want to pay out. Do you understand. I am going to tell you honestly, it is a way that people wants to commit murder. Then they are going to get away with murder. Schizophrenia- I am not nou a doctor, hear me, you have to understand me now, I am not a doctor hear me, but what I can say, né, is that schizophrenia he does not control your body. Am I correct, you have to say if I am wrong né.*

*C: Yes I am interested in what you think.*

*Eugene: Schizophrenia does not control your body. Do you understand. That thing controls my body, he makes me- I can walk in the roads and then he can...uhm throw me under a car and then the car can knock me over and then I can...you understand what I'm trying to say.*

*Eugene: Uhm, but they always come to mistreat people and things. They want to move forward, but if they are finished with mistreating you, then they say: go to hell we are done with mistreating you. You know mos how people are. People will mos do anything, né. Where money is involved, people will do anything.*

*Eugene: Yes I sommer say it's rubbish that does things like this to other people, understand. He isn't a human that does things like this to another person. Understand madam. Sorry that I dingese- but it's mos not a person that does things like this to another person. It's rubbish. A person that does things like this to another person is rubbish. He- he is not a person. He is a pig. He is a pig.*

**Lisa.** Lisa is a 32-year-old, coloured woman who speaks English and self-identified as Catholic. After completing secondary school and obtaining a diploma in marketing, she has been working as a financial consultant, with an income of R8000 per month. Her family members consist of her mother, father, brother (also diagnosed with schizophrenia) and two sisters; she described them as supportive and caring. She lives with her family as well as her husband, to whom she is happily married. They have no children, due to her comorbid illnesses of diabetes and rheumatoid arthritis. She receives a monthly antipsychotic injection.

Like DJ, Lisa seemed high-functioning, articulate and intelligent. She was friendly and open towards me. She described herself as leading a healthy, normal, and happy life, especially compared to her brother who is the “worse schizophrenic sibling”. I was surprised at how she

referred to her illness as her baby that she must take care of (“my mom says my conditions are my babies. I must take care of them”) and how nonchalant she seemed about the consequences (“now I can’t have children, which I am a bit sad about, but there’s nothing I can do”). She also stood out in the sense that, instead of being mistreated because of her differences, she felt “spoilt”:

*Lisa: My sisters would say I was the spoilt one, because I was just- my mommy would say I would just say eh! and then I would get. (laughs) I would just say I want this and that, I would want a phone and my daddy would buy the phone or whatever. So they would say I was the spoiled one.*

**Power.** Power, a 28-year-old woman, speaks both Afrikaans and English and is a member of the Anglican Church. At the time of the interview, she was single and lived with her mother, father, twin brother (who is also diagnosed with schizophrenia), and sister. She completed primary school and now irregularly cleans houses for an income. She remarked that she began feeling ill in 2007. What followed were years of numerous hospitalisations, injections, and pills.

In contrast to Lisa, Power appeared scared and anxious throughout the interview. She trembled, fidgeted and breathed heavily, whilst avoiding my gaze. Her body language stood in stark contrast to her friendly face and inviting smile. During the interview, Power was not spontaneously talkative, but always willing to answer a question, and grew progressively more uncomfortable and restless as the interview continued. Of all the participants, I was the most emotionally moved by her and felt protective towards her (perhaps because of her child-like innocence and vulnerability). She spoke of only feeling safe with her mother, describing her childhood years as follows:

*Power: Oraait. Most of those times were oraait.*

*C: Hmm. Most of those times were oraait. And the other times?*

*Power: Not so oraait.*

*C: Do you want to tell me a bit about that?*

*Power: My mother watches what I do at home. If I do something wrong, then she tells me.*



**Boom Boom.** Boom Boom is a 27-year-old Muslim man who speaks Afrikaans. He completed Grade 10 and currently works at a courier company (R5500 income per month), complaining that the job can get “too much”. He is divorced, with one child, and lives in a house with his mother, brother, sisters and extended family. Even though his mother is supportive, he feels that he has to bear most of the responsibility for the household. They live in a dangerous community where gangsterism is rife. He mentions that he started having sleepless nights during 2007, but realised that he was sick during 2010; he now receives Fluanxol injections. He refers to playing rugby as his “passion”.

Boom Boom came across as being talkative, spontaneous, confident (even grandiose) and, as he refers to himself, a “people’s person”. Due to a warning from the nurse that he has the potential to become aggressive, I sat close to the door. As a result, I struggled to become immersed in what he was saying, cautious not to provoke him. He spoke of being ambivalent about his father: on the one hand, his father was a sort of role model during his childhood, but on the other hand, he reported that his father was unsupportive and absent in his life.

*Boom Boom: Ag...what I am trying to say is...I went to my father a lot. No matter he jolled (had relationships with other women) or whatever, even if he had another wife, I was the only one- still now- go to that woman. I always went to him, man. Even during holiday times- I didn't worry if my father jolled- I didn't- I didn't- you know when mother and father breaks up, then the children sommer don't worry about the father anymore, you see? You know. And what happened to me is, I always worried about my father, sjoh. (gets emotional) That man didn't even support me, then I will just pay. And my father did- the same that happened to me- happened to me. I have- I have a son- but what happened was, uhm...my father wasn't always there for us, man.*

*Boom Boom: And uhm...what happened was, all those things came back to me. My mother who divorced my father and...and my uncle that- my auntie that stabbed my uncle- she stabbed him 15cm from the heart...and things like that, man. A lot of things that happened. And I told my father, if you were here- forgive him his- but if he was here, I wouldn't have gotten ill...so.*

He talked about being bullied at school, being abused by his ex-wife and being a “lover, not a fighter”. However, he also told stories of himself being aggressive.

*Boom Boom: But okay, what happened was...uhm...I was at school then. And I couldn't read very well like I said. They teased me a lot. A lot. At school. It's not a nice issue, really, because why. I can fight very well, but I never lig my hand vir iemand nie (lifted my hands for someone i.e. hit someone)- once I fought at school, but that was long ago. But I'm not a fighter, I'm a lover. (laughs) I love people a lot. I can mix with anyone- what happened at school was...as I read né, then the kids in class would laugh at me. I was...it was very bad yes. At that moment I took it as a joke you know, but okay. Nevertheless. But that is one of the main things wat my afgekraak het (that broke me down).*

*Boom Boom: She [ex-wife] abused me a lot, joh- my sister's child thinks it's a joke today- but I sommer get a hiding that time...but the nicest of it all I never really lig my hande. I would aim, aim and then I said to myself: if you are really going to hit this woman one day you are going to kill her.*

**Rudy.** Rudy is a white, 30-year-old, Afrikaans-speaking man of Christian religion. He completed secondary school as well as college and currently receives monthly grant money. He lives with his father who looks after him; he also has a brother who lives overseas. He recalled that he started feeling different approximately 5 years ago, and now takes pills and receives an injection.

Rudy spoke almost inaudibly and slurred because of his dry mouth and swollen tongue, possibly extrapyramidal side-effects of the medication. As with Power, I was reminded of a harmless, shy, innocent, and child-like vulnerability, also manifesting in the frequent use of the diminutive in his narrative. In contrast to this image, he showed me his various tattoos (symbolising peace, happiness, and joy) as well as the scars on his wrists and mentions, in passing, that his friends can be a bad influence. Looking at his narrative, he portrayed the image of someone who has experienced difficult and emotional times that are still unresolved (like the death of his mother, which he describes as “I don't take it to my head”) and therefore rather lives in the confusing present.

*Rudy: Then I would think maybe someone died there and maybe this person is talking to me- a little girl. My cousin and them come and they see- or they also hear things. But they seker imagine things to themselves also, man. The roof and the tree that sound like*

*that...it can maybe also happen in schizophrenia, né. So I don't know if it is just my friends...but maybe- the house is old- a young girl- maybe I am hearing a young girl.*

*C: A little girl.*

*Rudy: Something like that. Maybe it is nog my mother. Something like that.*

*C: Maybe it is your mother?*

*Rudy: It can be, I can't tell. I don't know. It can also be that I am alone in the house, then I imagine seker maar. But I am seker only tired. Yes.*

*C: Okay. Okay. And when did your mother pass away?*

*Rudy: Say maar 11 months ago...around then.*

*C: Oh 11 months. Oh sjoe, okay.*

*Rudy: Yes, but okay it is nogal a lot for me. So ek vat dit heavy op (it is difficut for me).*

*C: Vat dit heavy op. Sjoe Rudy.*

*Rudy: Yes...because of cancer.*

*C: Cancer, sjoe.*

*Rudy: Yes. My father is going overseas then I am going to stay with my family.*

*C: Okay. Okay. And how was your mother- how was your relationship?*

*Rudy: Good, it worsened a bit because of the cancer. Worsened a bit because of the cancer. So. Nobody knew that she had cancer and then she just died.*

*C: Sjoe.*

*Rudy: We were all very shocked.*

*C: Very shocked.*

*Rudy: Yes...but I am not really taking it to my head, but okay.*

**Noli.** Noli is a 27-year-old, black, isiXhosa-speaking woman. She lives with her boyfriend, who is also the father of her son, describing him as being helpful. She completed secondary school and is currently unemployed, receiving monthly grant money. She is originally from the Eastern Cape, where her father, mother, and four brothers still live. Her father calls her each morning to enquire after her sleeping patterns and whether she has taken her medication. She remarked that she has felt sick since the year 2009 and that she receives Fluanxol injections so that she does not hear voices.

Noli was very distracted by her toddler during the interview. Appearing distracted, she did not respond to questions such as “how did this feel?” and “why do you think this happened?”

However, she reflected on how her delusions seem to echo aspects of the community where she grew up and how, when the church tried to cleanse her with “holy water”, she ended up in the hospital. Nearing the end of the interview, she also - with what appeared to me as flat affect - told me about the traumatic death of her beloved brother.

*Noli: Yes and also the last time things go bad in 2012, because I come to hospital again. I were there for three months...four months. I can't remember whether it's two or three months. After my brother got hit by a car. Hitten by a car, my brother. It was that in 2012 and then I...I was fall asleep on hospital again.*

*C: And the fall asleep, what do you mean with that?*

*Noli: I would go to sleep at hospital again.*

*C: Okay and why that time, why did you go to hospital that time?*

*Noli: I go to hospital. I think...think I was...shock. Too shock.*

*C: Shock. Sjoe, so that time was a shock for you?*

*Noli: Yes. And then I was asleep- because he was- my younger brother that time- my younger brother called me and he was crying a lot over the phone and saying Z is dead and then I tried to wake up my sister-in-law and then my brothers and then we run to that road. We go there and then I saw him...put the black plastic over his body and then they said he's dead already.*

*C: Sjoh. That must have been traumatising. So you felt shocked and what else did you feel?*

*Noli: I...at that time I would not accept that situation. I tried to accept it. Because in that time we would go to the hospital, when they talk that- they say we go to look him there. I will think he was in hospital, but it was in mortuary. In my month I think they gonna come back with him.*

*C: Sjoh. And how do you think did that have to do with the sickness?*

*Noli: I think it affect my sickness.*

*C: Hmm, in what way?*

*Noli: Because that my brother was close to me. It is that brother I will sleep on the dining room with him that time I tried to run away. Yes it was him.*

*C: You were close to him.*

*Noli: Yes close to him.*

**Savanna.** Savanna is a single, 44-year-old, coloured, and Afrikaans-speaking woman. She has no religious affiliation. After completing Grade 11, she enjoyed being employed, but currently is not functional and cannot work. Savanna lives with her mother, sister and three brothers (one who is also diagnosed with schizophrenia). She mentioned that since she was diagnosed with “the schizophrenia thing” 5 years ago, she has been receiving injections, although she dislikes the needles.

Savanna appeared cautious and friendly. She, like Power and Rudy, had a child-like innocence that I felt guilty to disrupt by asking and reminding her about her experience of psychosis. She wore her emotions on her face: she smiled when she spoke of things that she liked (her sister’s baby, athletics, playing darts, knitting) and became teary when she talked about difficult times (the death of her father, unemployment). During an emotional moment, she said that she experienced immense loss when her father passed away:

*C: Tell me a bit about your teenage years?*

*Savanna: Okay. It was happy years. I had my father in my life. My father died, when I was 21. So, I knew my dad.*

*C: Hmm, and how was he?*

*Savanna: He was very strict. Not like my mother, my mother is a softy. (giggles) But she does not allow people to walk over her.*

*C: So, your dad was strict-*

*Savanna: The strict one. Yes, we had a very good relationship.*

*C: I can see that you smile when you talk about him. And, how was it for you when he passed away?*

*Savanna: It was as if I lost a friend, he was like my friend, like my best friend he was, and I lost a lot when I lost him.*

*C: Sjoie. You lost a lot-*

*Savanna: Yes- when I lost my dad, I lost a lot.*

*C: And how was the years after that...getting used to him being gone?*

*Savanna: It was a bit difficult. He was very supportive. He had his own car, he was very independent. He was a good role model. He was a lovely person- everyone liked him. He talked*

*to everyone. He had lots of friends. (gets emotional) And I wish that I could see him again, I wish that I could see him again.*

**Kloeks.** Kloeks is a 31-year-old, coloured, Christian man. He completed Grade 8 and is currently unemployed and homeless, after his mother kicked him out of the house. Of this, he remarked that “she knows why she kicked me out, I don’t know.” He also has a father and two brothers who live in the house. Of his experience of schizophrenia, he remarked that it began almost six years ago, but that he cannot remember. The injection worked well for him, but he goes to the clinic irregularly.

Kloeks abused substances and appeared dishevelled and neglected. During the interview, he seemed restless, irritable, evasive, and suspicious. He repeatedly insisted that everything is good and that he deals with things by “just getting over it”; not engaging deeper levels. I grew frustrated with this disengagement and was left wondering about my countertransference reaction of feeling used.

**Jappie.** Jappie is a 28-year-old, coloured, English-speaking, and Muslim man. After completing Grade 10 and attending college, he has been struggling to find employment. His family members include his mother, father, two brothers and two sisters. They live in a community with widespread violence and gangsterism. After starting to feel ill approximately six years ago and receiving injections and tablets, he now often misuses substances, claiming that it is his medication.

Jappie was talkative and well-mannered during the interview, but his narrative grew delusional and incoherent, permeated with neologisms, as the interview progressed. He also moved around on his chair, fidgeted with a sore on his finger and breathed heavily. I found him overbearing and struggled to warm up to him as I felt like he leaned uncomfortably close to me, making direct and consistent eye contact and exhibiting affect incongruent with his thought content. However, he told a powerful story of an abusive relationship with his father:

*Jappie: My daddy used to hit me also, and I was a young child, you know the wrestling, he chokes you on the bed? (giggles) Because he thought I stole money, but I did steal money already and- so that’s why he done that. He hit me also on my bum, is blue. So mother said we must go to the police station, man, because to make a case for him, so I did- we did not do that, so we left him.*

*C: Sjoh, so he hit you, but you- and how did it feel?*

*Jappie: It didn't feel right for me, it was sore.*

*C: It was sore, yes. Sjoh, and you didn't go the police in the end?*

*Jappie: No. I grew up in the right way, I had manners, I had respect and discipline, but my daddy was disciplinary.*

*C: Hmm. Okay and tell me a bit more about him? He sounds quite strict?*

*Jappie: Hmm. Yes all my friends are scared for my daddy, (giggles) they have respect for him, you can sommer see the type of guy and he gets quick cross- aggressive, man. And they have respect for him, they talk nicely to him, nice words. Nicely.*

*C: Okay so they're almost scared of him. And you, how do you feel?*

*Jappie: Of course I'm scared- afraid of him, because he's old, he hits sore and so. I've always opened the door, so, I'll always open the door. (giggles)*

He also, in his innocent and uncertain way, spoke with pride of his previous job as a general assistant, where he was fired for shoplifting, even though he did not seem to realise that he was stealing:

*Jappie: I can work, I was a very hard worker. I worked by that shop, I was the best worker there. I was a general assistant- the general assistant work everywhere. They work in the- there where the truck deliver- the courier- they deliver something and I worked there also and then I take it out- the items- of groceries and I dinges- I pull it with a jack- with that tool- then I jack it up and then I take it to the store.*

*C: Okay. And what happened- did you stop working there?*

*Jappie: Yes, because we could first take things for free there- but the last time when they- the cops came to fetch me, because I take Regall sweets and porridge- that instant porridge- so I took strawberry porridge- and so I put it in my bag, man, so I thought I could have taken still, so they searched my bag and they find it there, so- because the security what was there was- they called me, man. So I- so the- the supervisor told me to search my bag and the security got something in my bag, so it is and so they phoned the police and they took me to the jail.*

*C: They took you to the jail.*

*Jappie: Hmm, so they bailed me out.*



*C: So you thought that you could take something for free still, but then you couldn't.*

*That's not a nice experience- the jail. How did that feel?*

*Jappie: It was very upset.*

**Pieter.** Pieter is a 26-year-old male, who identified as Afrikaans-speaking and Coloured. He completed Grade 11 and was unemployed at the time of the interview. He lives with his mother, two brothers and a sister, with whom he has a good relationship, while his father is absent in his life. He began feeling sick during 2009, while he was frequently abusing substances such as alcohol, methamphetamine, marijuana, benzene and glue.

When I met Pieter, he appeared well-mannered and concerned with his appearance. He was also shy as well as evasive and exhibited a paucity of speech and restricted affect. He seemed to hold his sickness and the drugs responsible for acting without thinking:

*Pieter: So...I can't remember. When I used tik [methamphetamine] and smoked dagga...then I just got ill. Started to dance in the road and break people's windows and last time she realised I got ill, she sent me to the hospital.*

His narrative further mainly focused on the time since he stopped abusing substances and started focusing on his health. To me, the interview felt almost like an interrogation - as Pieter often struggled to remember and did not reflect on his answers at a deeper level ("I can't say *nog* much"). He often chose not to answer questions by shaking his head.

**Summary.** Participants often assured me that they were doing well and that they were coping and getting used to things and that they had no complaints. However, together with those reassurances, were experiences of being different, excluded, bullied, abused, mistreated, controlled, confused, exploited and subordinate in various ways throughout their lives. These traumatic histories of abuse and submission highlight the need to take individual histories seriously, even in people with a diagnosis of schizophrenia.

A recent national survey in Australia on people diagnosed with psychotic illnesses acknowledges the need to recognise and respond to other life course events that may adversely affect symptoms and the potential for recovery and quality of life in people with psychotic illnesses (Morgan et al., 2016). High rates of self-reported childhood abuse (30.6%) and adult victimisation (38.6%) are mentioned as major challenges linked to predisposing social



disadvantage (Morgan et al., 2016). However, it seems as if both childhood and adult trauma are still under-recognised in mental health services, probably because identification and treatment requires significant service development in the mental health sector (Morgan et al., 2016). Support for this can also be found in recent epidemiological research that identifies various environmental risk factors for psychosis that interact with a genetic and developmental predisposition to developing psychotic disorders or psychotic symptoms (Van Os et al., 2001). These risk factors are said to include early traumatic childhood experiences (Ucok & Bikmaz, 2007) as well as trauma experienced during adolescence and adulthood (Bechdolf et al., 2010), including for instance family difficulties, social isolation, bullying, abuse, discrimination, stigmatisation, marginalisation, post-traumatic stress disorder and other intrusive life events (such as events in which individuals experience others controlling them). Further support can be found in a quantitative review of available empirical literature, concluding that exposure to adverse childhood experiences are strongly associated with an increased risk for later experiencing psychotic symptoms (Varese et al., 2012). Also, large-scale population studies in America and Mexico show that experiences of victimisation and powerlessness might predict psychotic symptoms (Mirowsky & Ross, 1983). Also in South Africa - with high levels of poverty and violence during childhood and adulthood - a quantitative study of participants diagnosed with first-episode schizophrenia spectrum disorders reported that previous traumatic experiences is associated with positive and affective symptoms of psychosis (Burns et al., 2011).

An early form of victimisation, childhood bullying (including familial patterns of inclusion and exclusion), is now specifically being empirically researched as a part of the histories of people with a vulnerability to a psychotic disorder (Charles & O'Loughlin, 2012). Socially speaking, bullying is characterised by a power imbalance that can position the child as alien, inferior and isolated from peers and the social environment, possibly leading to feelings of hopelessness and inefficacy. This form of social exclusion and marginalisation has been shown to lead to shame and humiliation (Birchwood, Meaden, Trower, Gilbert, & Plaistow, 2000). From a cognitive perspective, another author theorises that this goes together with dysfunctional appraisals about the self and the world that might develop following bullying victimisation, such as hostile attributions of others' intentions, negative self-perceptions and lack of personal control over events (Trotta et al., 2013). If data from attachment and developmental studies about the importance of early relationships for resilience are taken into account, it makes sense that a

traumatic disruption in identity formation can be linked to a higher incidence of psychotic-like symptoms and even a higher risk of psychotic illness later in life (Kelleher & Cannon, 2011). Charles and O'Loughlin (2012) extensively write about how “people are driven mad by social exclusion” (p. 418).

Despite difficulties in establishing a definite causal link between childhood trauma and psychosis (Burns et al., 2011), the above mentioned studies highlight the importance of also focusing on psychological and subjective aspects in the histories of people diagnosed with schizophrenia that cannot be addressed by biomedical treatment alone (Bebbington et al., 2004; Birchwood et al., 2000; Charles & O'Loughlin, 2012; Read, 2005; Trotta et al., 2013; Williams & Collins, 1999).

### **Complex Emotional Worlds**

Interviews with people carrying a diagnosis of schizophrenia suggested that while all of them clearly had psychotic experiences, they also have complex, rich and diverse emotional worlds - not necessarily captured by the diagnosis of schizophrenia. Participants were explicit about the intense feelings that accompanied their psychotic experiences: fear, anxiety and paranoia; shame; anger and aggression; loneliness and isolation; and sadness.

**Fear, anxiety and paranoia: “I am afraid of people”.** For certain participants, their lives were permeated with feelings of fear, defined by the *APA Dictionary of Psychology* (VanDenBos, 2015) as a rational, basic, intense reaction to an objectively identified external danger or threat that may make a person avoid and escape in self-defence. In recalling her time at a psychiatric hospital, Noli remembered sleeping, being cold and feeling afraid:

*Noli: Yes, because I would like to sleep and then when I wake up I'm afraid and cold.*

*(moves body)*

*C: So the moving [refers to Noli moving her body]?*

*Noli: Yes shaking. I was shaking at that time. And then it was cold and then I was afraid.*

DJ described such a pervasive fear that he was even afraid of eating:

*DJ: Uhm like say for example when you, like, you are afraid of eating, because you are scared of the peas yeah but why and whatever for the food and whatever...then uhm*

*during that time of not eating you get like, like sour taste, or some kind of weird taste in your in your mouth and also, you start like hearing like uhm like uhm an inner voice, can be male of female, that's like talking to tell you: listen, uhm don't you want to do this and leave that and don't do that and...*

While fear is seen as a present-oriented and short-lived response to a specific threat, anxiety is considered a future-oriented, long-acting response characterised by apprehension and somatic symptoms of tension in which an individual anticipates impending danger, catastrophe, or misfortune (VanDenBos, 2015, p. 66). As found in this and other studies, anxiety or “stress” is not necessarily explicitly linked to psychotic experiences (Vodusek, Parnas, Tomori, & Skodlar, 2014). It rather manifests as a persistent and pervasive background of everyday life, a vulnerability or fear of everything over a long period of time (Vodusek et al., 2014). Regardless of the finer-grained explanations offered by the different theoretical perspectives, the experience of anxiety, especially social anxiety, has been recognised as a common feature of the experience of a diagnosis of schizophrenia (Vodusek et al., 2014). DJ, not being able to handle a lot of stress, suggests developing coping mechanisms to deal with stressful circumstances. Implicit in his accounts, seemed to be an experience of persistent and quite severe anxiety.

*DJ: Yes some people they can handle a high level of stress, but I can't handle that much stress. I can handle a- like say for example half stress, you know.*

*DJ: Also if someone gives you a little bit stress, then you must learn to handle that also, because that will make you stronger also.*

*DJ: Yes. It's very important for a person- say for example a person with an illness that's working to have an off time for themselves also, say for example they wanna go watch a movie or something with someone or ...alone or whatever. Just have me time. And then- or maybe Saturday and Sunday just rest for a little bit and so Monday you feel fresh and you can handle stress during the week or whatever.*

Anxiety has been found to be associated with paranoid thoughts and persecutory delusions - the anticipation of physical, social or psychological harm from external dangers (Freeman, 2007). Indeed, participants in this study reacted with fear and anxiety, but on the extreme end of the spectrum this manifested as paranoia, with the mistrust, hypersensitivity, and

vigilance typically associated with paranoia (VanDenBos, 2015). The paranoia and hypersensitivity were very evident in the following narrative of DJ:

*DJ: And then develop this attitude like uhm uhm no I can't eat this now, I must save this for later on and what is my father gonna to say if I eat this and if I go bath now I must not use up all the water and I mustn't bath to long and yes I mustn't use soap or something like that. You know. Like like you're more heightened sense of awareness like what people are gonna think of you, but actually in a case it rarely never happens.*

Leo and Eugene were afraid, anxious and paranoid about being poisoned by other people.

*Leo: Yes and I had- I was actually so te sê (so-called) afraid of them [family]. They can do something to me or poison me or so.*

*Eugene: You see, you see, what happened was uhm, I was already poisoned. They have done a lot of little things to me already. And the people just get away with what they do.*

Furthermore, Lisa appeared to display paranoia and vigilance in anticipation of physical harm from other people.

*Lisa: It was very- it wasn't a nice feeling and you're driving around and think people want to kill you or they want to hurt you, and...it was like paranoia- you had paranoia, so...it was a very bad experience.*

*Lisa: I was frightened and scared and I was thinking people want to kill me and things like that. And the only people that I could trust was my parents and things like that. So a lot of emotions and a lot of things- non-real things. People want to burn you and things like that. I plastered the air vents, because I think they were trying to smoke me out. So a lot of paranoia, thoughts that you had.*

The intensity of the annihilation anxiety can be so overwhelming that individuals fear losing themselves and ceasing to exist (Berzoff et al., 2011) - as evident in Eugene's narrative. He felt that he was being controlled, rendered powerless over his own body and even that he, as well as other people in the country, will be killed:

*Eugene: Yes, they control your body. Do you understand? They patrol with your body, né? Then it almost looks like I am under the influence of alcohol, but I am not a drinker. I don't use alcohol. Do you understand? Then it almost looks like I'm under the influence of alcohol, but if you take an alcohol test from me né, then you will see there's no alcohol in my body. The way that they control me, do you understand? Nou with control- like they control me I can under a car- walk in front of a car, then the car can run you over. Do you understand? And then later it looks like I'm under the influence of alcohol, but if they take an alcohol test from me, then you won't find alcohol in my body. It's the way they use it on people. I mean if they decide nou- if they can do it to me, tomorrow they do it to another person, then you can still say it's schizophrenia, then it isn't schizophrenia, then it is people's rubbish that they use on other people.*

*Eugene: A person has to speak with another person who is a person who knows what the whole story is about, because tomorrow the day after tomorrow the person does it to another person that gets away with it and if the person gets away with murder then tomorrow the person does it to another person and then the person gets away with it again, how is the murder statistics going to look in the country and how is the death statistics going to look in the country if...*

According to Berzoff et al. (2011), working from a psychodynamic perspective, feelings of fear, anxiety, and paranoia are frequently precipitated by a sense of loss, by frightening interpersonal contacts, and by the experience of powerful affects. Pao (1977) referred to this level of anxiety as organism panic, due to the experience of an overwhelming distress early in life, that “the predisposition to anxiety may become so enhanced that each time he should experience anxiety he experiences panic instead” (p. 394). Panic interferes with the development of a healthy ego and relationships with other people, causing the person with schizophrenia to use more primitive “tools”, such as denial, against conflict in order to relief panic. Semrad (1960) also wrote about how psychosis may be the best possible “solution” for overwhelming anxiety and intense affect that cannot otherwise be processed, capturing the level of distress experienced by people with schizophrenia (Adler, 1978).

**Shame: “I’m not human, like a monster”.** Morrison (1984) claims that shame is the most painful of dysphoric affects, reflecting harsh judgements about ourselves: an experience of

being defective, inferior, and unworthy. Shame is what we feel when we do not get affirmation or when we fail to achieve an ideal. It is the experience of being exposed in a situation where the self is seen as a lesser and inadequate self (Seu, 2006). DJ's feelings of inadequacy, against the ideal of a normal human being, stretched so far in that he saw himself as inhuman - an alien or a monster.

*C: And what was that time like for you? Before the injections, getting used to things.*

*DJ: Uhm it was it was very difficult, uhm I actually hated it, because I felt like an alien like I don't fit in anywhere. You know. Yes.*

*C: An alien.*

*DJ: Like an alien, like (laughs) an alien from another planet or somewhere, I'm not like I'm not human, like a monster or something you know. Yes.*

Apart from his general feelings of shame, DJ is also ashamed about not functioning, remembering feeling unloved and useless before securing employment.

*DJ: Uhm partly it's this job that I'm doing here. It gives me, how can I say...uhm it makes me feel better inside, like I belong somewhere you know. Not like I feel like an outcast, like I'm sitting at home and nobody cares about me and I'm not earning money and I'm not contributing and I'm not doing anything so yes this job helped me a lot.*

Boom Boom also spoke of how not being able to financially provide for his family caused him to feel unloved:

*Boom Boom: Why are those people so excited and my own huismense (people at home) are not so... People outside are excited to see me, but my huismense- just when I have money then they are excited. Which is wrong. Which is wrong, you know. They are oraait with me, but when I have money then...now I'm their brother. What happened is- I thought nobody cares about me. That's what happened.*

As symptoms appear and individuals become aware of their diagnosis, shame can become overwhelming, with participants in numerous reviewed studies reporting feeling like failures, with a sense of shame at being diagnosed with schizophrenia and not being able to maintain control of their lives (Walsh et al., 2016). Amongst shameful descriptions of the

participants in this study of being inadequate, unloved, useless, and even inhumane, are descriptions of the shame associated with being diagnosed with schizophrenia. Boom Boom and Lisa described their actions as “stupid”, “silly” and like a “joke”.

*Boom Boom: But I acted stupidly you know, but I did not actually go on like that, I began acting like making jokes, but in the end I got ill like that.*

*Lisa: So a lot of paranoia, thoughts that you had and if I think about it, it's a joke. Not a joke, but it's a little silly. But that is what you believe at that time, it's like it's real, it's really happening to you.*

Lisa chose not to disclose her diagnosis to her friends, because she was afraid that they would treat her differently:

*Lisa: After my uhm- after two months or three months out of studies I went back to tech [technikon] and things became normal and things like that, obviously friends ask why I was out and things like that. I just said it was a condition and things like that, but I never went into it and they- I didn't want to disclose to them, because then they might treat me differently and that was what I was afraid of. No-one at work knows or anything, because there's a stigma attached to schizophrenia. Out there what the world perceives schizophrenia, and how the TV perceives schizophrenia and things like that, is completely different to what people really is. They make it so worse on the TV, so bad, that you think- when I'm watching TV and they talk about schizophrenia- the person has paranoid schizophrenia and they make the person so bad out that people out there in the world will think people with schizophrenia is like that. So, uhm, the stigma and the...the way they perceive schizophrenia is very bad.*

According to Power, people are afraid of the idea of schizophrenia, and also of her:

*Power: People don't want to- if they hear it then they get a fright. But that is not how it actually is.*

*C: Hmm. How is it actually?*

*Power: It's like something bad, it's like...*

*C: So if people hear schizophrenia then they get a fright?*



*Power: Yes, they think it's the devil.*

*Power: Yes my sister got scared of me. She got scared.*

*C: How did she realise?*

*Power: When I- when I told her [about the diagnosis], then I told my auntie.*

*C: And can you tell me a bit about when you told her, what did you tell her?*

*Power: Told her I can- people talk about me that people talk about me, I told her. But when I said that then she got scared.*

*C: How did she get scared?*

*Power: I told her there's a woman at the window, then she got a fright then she covered her head, then she got scared.*

Feelings of shame about being diagnosed with schizophrenia have been shown to be connected to negative self-thoughts and internalised stigma (Walsh et al., 2016). Stigma, defined as the negative social attitude related to a characteristic of an individual that may be regarded as a mental, physical, or social deficiency, implies social disapproval and can lead to discrimination against and exclusion of the individual (VanDenBos, 2015). There is substantial evidence that mental illness, especially schizophrenia, carries severe social stigma in many societies (Burke, Wood, Zabel, Clark, & Morrison, 2016; Kakuma et al., 2010; Mestdagh & Hansen, 2014), also in South Africa (Kakuma et al., 2010; Mbana et al., 2002), often further re-enforced by the media (Roe & Davidson, 2005). A South African study with family members of Xhosa-speaking patients diagnosed with schizophrenia and living in Cape Town, believed them to be dirty and dangerous (Mbanga et al., 2002), whilst Sesotho-speaking patients with schizophrenia in Pretoria reported feeling misunderstood, rejected and persecuted by the community (Motlana et al., 2004). In Botha et al.'s (2006) study of the perceptions of individuals diagnosed with schizophrenia in the Western Cape with regards to community attitudes towards their diagnosis, more than half of the 100 participants agreed that they felt discriminated against. This kind of stigmatisation, especially toward low-income patients, can act as a barrier towards recovery and cause persistent suffering, disability and economic loss associated with mental illness (De Wet, 2013).

In combining social and cognitive models, Birchwood et al. (2006) devised a stigma model of shame in schizophrenia. They theorise that many individuals diagnosed with



schizophrenia can internalise culture-wide stigmatised beliefs about the diagnosis and associated symptoms. Once these cultural beliefs are internalised, these individuals might have concerns that others perceive them as part of the stigmatised, marginalised group, viewing the self as inadequate. During a psychotic episode, individuals are then vulnerable to a so-called catastrophic shaming belief of feeling devaluated and, as a result, suffer from shame and diminished self-esteem (Birchwood et al., 2006). Birchwood et al. (2006) further believe that this individual will then continuously monitor for threats, both in what others are thinking and what the self is displaying. A qualitative study conducted in England, indeed found that stigma appeared to be an overwhelming source of worry for participants with psychosis (Burke et al., 2016), leaving them with a sensitivity to how they measured up against what they understood as other people's expectations of them (Williams & Collins, 2002). Lisa described feeling worried and preoccupied with what others might be saying or thinking about her and "what they will think if they find out":

*Lisa: I was very frightened and scared and worried what people will think if they find out and the delusion- not delusion- what do you call it? Where you, uhm, like uhm, you thinking people's coming to kill you and things like that. So that was very frightening at the beginning and things like that.*

*Lisa: Uhm...I was very frightened. Frightened and scared and worried what people's gonna think...and things like that, but we just kept it between us in the house. No-one really knows. The only person who I really confessed to that I had schizophrenia was my mommy said- to my husband to tell him that if him and I gonna get serious or whatever he needs to know what conditions I have.*

Together with monitoring for what others might be saying and thinking about them, individuals diagnosed with schizophrenia might aim to conceal their diagnosis and present well, which often functions to increase their social anxiety (Birchwood et al., 2006). Perhaps most relevant here is how participants tried to illustrate their popularity and moral goodness:

*Boom Boom: Now you know what- I am a people's person. That is the kwaaiste (coolest). Sjoh. I know if I die someday...I don't think a train will be big enough. Serious girl, serious. I know that many people.*

*Boom Boom: I am a very good person as you can see.*

*Jappie: Maybe by being humble I talk to children about words- I learn them from right and from wrong, from gangsters, gangsters made up wrong words- you know- they made up wrong words that don't fit in the vocabulary of- they talk their own words out. They say duidelik and in Afrikaans it is verduidelik (explain). I learnt a lot of things about them, through the drugs that is, because they also smoke drugs, man, but I'm not a gangster- I'll never be a gangster. I'm a gentleman.*

**Anger and aggression: “I get like angry in my mind”.** In the *APA Dictionary of Psychology* (VanDenBos, 2015), “anger” is defined as:

An emotion characterized by tension and hostility arising from frustration, real or imagined injury by another, or perceived injustice. It can manifest itself in behaviours designed to remove the object of the anger (e.g. determined action) or behaviours designed merely to express the emotion (e.g. swearing) (p. 55).

Anger was explicitly mentioned by Rudy and Kloeks:

*Rudy: Uhm, I think I was a little bit jealous [refers to ex-girlfriend].*

*C: Hmm.*

*Rudy: Hmm. Okay that's my first girlfriend- I began to get angry at her. Now it also werk op my (bothers me) why am I sitting at home, what did I do what did I do.*

*Kloeks: I say the injection helped a lot.*

*C: How did it help, what changed?*

*Kloeks: I...don't get angry as quickly anymore.*

Anger is distinct from, but a significant activator of, aggression, often evident in schizophrenia, as shown by international (Birchwood et al., 2006) and South African studies (Motlana et al., 2004). While anger is oriented at overcoming the target, but not necessarily through harm or destruction, aggressive feelings and behaviours in the form of a physical or verbal attack, can cause psychological or physical harm to another individual (VanDenBos, 2015). DJ's narrative demonstrates the transition from feeling angry and keeping quiet, to “not being able to take it” and becoming verbally aggressive in opposition to a nurse:

*DJ: Uhm yes I get like angry in my mind, but then I mostly just keep quiet and don't get physical or anything. There was one incident with the sister [nurse] where she called me and I was smoking outside and I came in and she- like she told me she didn't- she wasn't shouting at me she was being stern with me, so just I couldn't take it so I just shouted back and she told me you mustn't shout at me, I'm just being stern. So but then everything was okay after that.*

Boom Boom described acts of verbal aggression in opposition to family members, not necessarily with the intent to cause harm.

*Boom Boom: They would maybe just say- okay they didn't say it like that, but then I said sommer so- I almost said- I don't like it when someone says I am crazy. Because why it's not nice. I was already sick, why must you tell me that I am crazy. Uhm, and then I got angry in the house, joh I got terribly angry while my sister- she's my best sister- then I just want to fight with her- not fight, scold, scold. I will never beat her, that's not me. I will just maybe say: I will donner you. But I said it in a swear way.*

Aggression is also associated with violence, the expression of rage and hostility involving physical force intended to injure or damage people or property (VanDenBos, 2015). In some instances, the underlying anger or aggression did result in violent behaviours by the participants in this study, so-called “uithak” behaviours leading to the destruction of objects and/or harm to other people. Pieter talked about breaking windows during a psychotic experience:

*Pieter: Yes, my head just began to hurt, from the drugs nou. Then I started to uithak (loose it). End up here.*

*C: Okay, and you say uithak, what do you mean by that?*

*Pieter: Like...I didn't think what I was doing. Did things, from getting sick and so.*

*C: Hmm, okay. And what things did you just do without thinking?*

*Pieter: Like...smashed people's windows...and so forth.*

Another participant, Boom Boom, recalled acts of physical aggression towards his ex-wife and during an incident at a mosque:

*Boom Boom: I am talking softly now. (laughs) If I growl then I talk loudly. But what I am trying to say is, uhm...what I am trying to say to you is, I had...I had...I loved my wife very much, man- I still love her. Joh. For the first year she was the best wife on earth. Joh. Is...is almost like if I go to heaven one day, I want her there again, but now I want her in hell- I don't tell her that, but I'm making a joke. I want to see her in hell and if I am in heaven then I will tell her goodbye because I lived the right way. Once I lifted my hands- I mentioned it to you now. She gave me four slaps, the reason why. You know what deurmekaar raak (cheating) is, I cheated with a girl, the reason why I wanted my wife to leave me, because I saw things- I gave her two chances, but I saw that things weren't getting better. Then she gave me four slaps. Then I pushed her over, but then I also pushed her father over. Not pushed over, but pushed aside to get away, because I've never beaten a woman- even slapped. In my life.*

*Boom Boom: I think it was on a Thursday was it on. Then I sat- but I had- the guy looked for trouble first. Then I sat- then I sat- I wear expensive shoes like you can see, then I put it there inside a little place that- almost like the- we are not allowed to with our shoes- and then he scowled me: hey why do you put your shoes in there, but he's the caretaker there. But he's a- a second in command caretaker. Then I said: but I didn't mos put my shoes on the carpet, I kept it mos in my hand. Then he said: boeta you mustn't- he has a nasty manner- it's a gangster guy, but he's a Muslim guy. And then I got angry when...he saw- then I wanted to fight him nou. Then I told him: you old man, what are you saying. Then I talked to him. I will hit you. He says: do you know me. And then he says: you, I will stab you with this knife now. And then I saw him pull out a knife and then I swore at him. In the mosque, in the church. He wasn't even drunk- in the church, my sister [refers to me]. Then I ran and said stiek uit and picked up a stone, then my nephew was there also- the one that also gets sick. Joh, then it was bad for that guy. Then I told him: my bru, my boeta, my cousin is a big man, you are going to get hurt, we are going to hurt you. Leave this man. We are close nephews. We were close nephews, because when we got sick- before we got sick. But then we wanted to attack him. And then I said to him: naai bru, don't be like this, man. Afterwards the next day I asked myself- then I apologised because then I was still angry at him- kwaad op my gehad (I was still angry) but it, but it is gone now.*

In contrast to the typical public beliefs of a person with schizophrenia as violent and unpredictable (Mestdag & Hansen, 2014), the DSM-5 reports that the majority of persons with schizophrenia are not aggressive and are more frequently victimised than other individuals in the general population (APA, 2013). However, anger or rage is still understood by some theorists to be at the core of the schizophrenic person's emotional life (Robbins, 1993) and hostility and aggression have been shown to be associated with schizophrenia, more frequent with younger males and with individuals with a past history of violence, non-adherence to treatment, substance abuse, and impulsivity (APA, 2013). While anger was very prominent in the emotional profiles of the participants in this study, it seemed to always be connected to their feelings of fear, anxiety, and paranoia, as well as the shame they feel in the presence of certain people.

**Loneliness and isolation: “There’s nobody and nowhere to go”.** The complex emotional worlds of participants included fear, anxiety and paranoia as well as shame. These feelings seemed to be connected to feelings of anger and acts of aggression and sometimes violence. This fear, anxiety and paranoia as well as shame also often went together with feelings of loneliness and isolation. For people diagnosed with schizophrenia, the world is often perceived as foreign and threatening (Hirschfeld et al., 2005; Vodusek et al., 2014). Evolutionary speaking, when individuals feel threatened in a potentially hostile, rejecting environment, this will alert them to their relative lower social rank and lack of social power to protect themselves (Birchwood et al., 2006). The withdrawal from the emotional directness of the world that follows often provides a haven for people with this diagnosis from the frightening unpredictability of external circumstances (Sass, 2007). Individuals are then often left with concerns about their ability to connect with other people (Williams & Collins, 1999). In other words, feelings of isolation are said to begin in the context of psychosis when bewildering experiences create a barrier between the individual experiencing psychosis and the rest of the world (Williams & Collins, 1999). Participants in this study actively tried to protect themselves by escaping, avoiding, withdrawing, secluding and isolating themselves.

*Lisa: That was frightening and scary, because I felt like they wanted to kill me. I jumped out of the window [of the psychiatric hospital]. I tried to run away, ‘cause I didn’t know and then I found my parents and they were worried and concerned and they had to come all the way back.*

*Eugene: The other day I said, uhm, that I am going to Durban for a whole month- going me and the captain [of the police]. A whole month we are going to Durban. We are only going for me- then we are going to Durban for a whole month, if it is nice in Durban I will sommer stay there and also buy a house for me there, then I stay sommer there. Then the Western Cape will never see me again. The Western Cape...the people in this place are...jealous of each other and they go after each other and they go after each other.*

*Noli: When I wake up [in the psychiatric hospital] and then I was- also there I was tried to escape, but when I go to the reception I see the people stayed there and then I tried to open the door was at the back and then a sister [nurse] see me and take me to the back again and then another sister come take me to the hospital.*

*Leo: Yes I locked myself in my room and I did not trust them [family], in the house. Yes. Almost like I was afraid of them.*

*C: And at the end of the interview now, we talked about a few difficult things for a long while. How are you feeling?*

*Leo: No okay I feel satisfied.*

*C: Okay. Satisfied in what way?*

*Leo: Yes, just glad that I came. I didn't feel like coming. Yes and I am used to kluis (isolating) myself in the house.*

*Power: The stuff- stuff like what I feel, afraid of people, don't want to come out.*

In DJ's case, he even attempted suicide.

*DJ: Uhm yes I uhm, I- as I said before, when I was very ill I was always concerning what people are like outside. I was scared to go outside, I was scared to dress and normal things, I was scared of eating and even go to the shop to buy a loaf of bread or milk and then uhm I came to a verge when I tried to commit suicide...by slitting my wrists, but then I recovered again.*

People who isolate themselves frequently experience a desperate sense of loneliness. The APA Dictionary of Psychology defines "loneliness" as "affective and cognitive discomfort or

uneasiness from being or perceiving oneself to be alone or otherwise solitary” (VanDenBos, 2015, p. 610). Social psychology research emphasises the emotional distress that can be experienced when inherent needs for intimacy and companionship are not met (VanDenBos, 2015). Participants talk of being alone, without friends who can relate to them.

*Leo: I almost don't go out of the house and most of the time I'm inside the house.*

*C: Okay most of the time at home.*

*Leo: Yes I don't have friends.*

*DJ: Yes the people with schizophrenia they're alone. There's nobody and nowhere you can go. There's only themselves and maybe the doves [referring to the doves outside the office window] if they want to.*

*Rudy: I am alone now. So I take everything onto my shoulders, a lot of things that I think about.*

DJ mentions that people diagnosed with schizophrenia even talk to themselves out loud as an affirmation, because nobody seems to understand them on their level:

*DJ: And also what I forgot to mention is how in some cases patients not yet diagnosed they're still ill, they start to talk to themselves. Because there is nobody else that understands them at their level. Or maybe they don't have money to see a private psychologist or whatever. So they talk to themselves all the time. Like an- like an affirmation of like they're affirming to themselves: yes, I'm going to do this, and yes, I'm going to do that. Yes. So they can affirm to themselves that I'm thinking this and this is what I'm gonna do, this is what I'm gonna do, this is what I'm gonna do.*

In these descriptions of intense loneliness, of being alone in their understandings of themselves, is a need to belong and relate to a community. This is in accordance with international (Berzoff et al., 2011; Hirschfeld et al., 2005) as well as a South African qualitative studies (Bradfield & Knight, 2008; Zubi & Connolly, 2013), reporting that a common experience of people with schizophrenia is a sense of pervading loss of interpersonal relationships, loneliness and social isolation often emerging out of being misunderstood. This sense of belonging to a community is usually found outside of normality, with other sick and



marginalised people that can provide a sense of camaraderie (Birchwood, 2003; Mestdagh & Hansen, 2014; Zubi & Connolly, 2013), or in the words of DJ: “so we’re going through the same thing, so you don’t have to worry, we’re not alone”.

*DJ: So they can't- they don't understand, not that I'm saying normal people are bad, but normal people don't understand what the sick person is going through like a life-threatening illness like schizophrenia or whatever.*

*DJ: So every day I came to move away from that environment and to associate myself with other people that also have the illness so that I can communicate with them at the same level. So that it is very important to get along with other people that have the same illness as you, not to seclude yourself, because once you seclude yourself that's when you become ill.*

*C: And do you have people like that?*

*DJ: Yes I have I have a friend, he's a bodybuilder. Yes. We hang out, we go to a center we watch a movie and just talk about maybe girls or something like that you know. Did you watch this movie, I said yes I watch that movie, can I you get this movie, yes they copy music for me and say yes I will copy music for you and they say okay are you hungry my friend, and I say yes I'm hungry now, you wanna buy half a Gatsby and say yes you put a half and I'll put a half and we buy our Gatsby and just sit there and I say yes how's your sister and he says yes my sister she's okay but last week she was giving me problems man, you know. Like, like something like that you know. And then if his mother and father tells him: listen, works on his nerves and gets angry with him when he feels depressed, he just phones me and tells me: listen I'm feeling depressed, because of this and this and I said: my friend, don't worry so much, my mother and brother is also the same with me, so we're going through the same thing, so you don't have to worry, we're not alone. (smiles)*

Other studies have also found a link between the experience of shame and stigma, and anxiety, loneliness, and isolation. A recent Australian national survey on people diagnosed with psychotic illnesses quantitatively reports that 68.8% of their participants cite an experience of social anxiety and shame in the presence of certain people, especially people with a stigma against such diagnoses, to be barriers in participation in social activities, leading to severe



loneliness and social isolation (Morgan et al., 2016). This has led numerous studies, also in South Africa, to advocate for psychosocial and aftercare treatment programs and psycho-educational groups to address loneliness, the loss of friends and the lack of support in a community setting for individuals diagnosed with schizophrenia (Kotze et al., 2010).

**Sadness: “Then I get quiet and and I get weepy”.** Feelings associated with depression (feeling “sad”, “depressed”, “weepy”, “moody” and “emotional”), were also prominent in the emotional profiles of participants. Sadness defined as “an emotional state of unhappiness, ranging in intensity from mild to extreme and usually aroused by the loss of something that is highly valued” (VanDenBos, 2015, p. 930) was explicitly mentioned by Boom Boom, Noli and Rudy:

*Boom Boom: My sickness is different, but if I- you get mos schizophrenia and then you get bipolar. Like bipolar I have seen people get violent. Schziophrenia- people also get violent, but say for example I get sick then I get quiet. That’s what happens to me. Then I get quiet and I get weepy, so.*

*Boom Boom: But what I’m trying to say is- yesterday I was a bit depressed. She [ex-wife] was very jealous, oh jinne. (laughs) She was very jealous. But...(sighs) she was a good wife.*

*C: But it made you a bit depressed yesterday when you thought about it?*

*Boom Boom: Yes, but what happened is...after I cried- I cried. What made me cry- I listened to Love Songs a bit and then I thought of my wife and my child who aren’t with me anymore- and then I said to myself, yes. Look at how nice that family is laying, because they were already in the kooi (bed).*

*C: And maybe something that you would tell someone else who’s been through the same things? Something that helped you maybe?*

*Noli: And then I would talk to someone how I feel today. Or maybe if I- today I’m...sad, I talk and say today I’m not alright and try to...*

*C: Okay so try to talk to someone else. And tell them today I’m not okay. Okay you would do that. And who would you talk to?*

*Noli: I talk to his [refers to baby] father.*

*Rudy: I told hom [friend]. Don't worry, just go home. Maybe it is because I'm getting older, I get emotional.*

*C: Maybe?*

*Rudy: Emotional. Sad. If my mother and them can't be there, then what then?*

*C: It's almost sad times.*

*Rudy: Yes sad times.*

Lisa described not only being very down, but also referred to quite severe mood swings. "Moody" is described as unpredictable changes of mood in a person, especially sudden bouts of gloominess or sullenness, giving an impression of melancholy or mystery (Oxford University Press, 2016).

*Lisa: You're feeling tired, you're feeling drained, you're feeling- you're up and then you're down and then you...so...*

Savanna specifically referred to having unpredictable mood swings that impact on her daily functioning and on self-care.

*C: Nou how do you know then, if the schizophrenia is with you? How is it then?*

*Savanna: It's- it's a mood that I can't explain. It's just a mood.*

*C: A mood?*

*Savanna: Yes. It's...it's as if I just get moody. And it comes and goes. It's like moodswings.*

*C: Okay, so. There you found words for it. It feels like a moodswing.*

*Savanna: Yes.*

*C: Hmm. The mood swing comes, and it also goes.*

*Savanna: Yes.*

*C: How does it feel when the mood comes? Or what do you do?*

*Savanna: I just feel a bit down. And then I just sit at home. Then I sit and do nothing.*

*But, uhm, there are times when I want to clean, and there are times that I don't want to do it. So it's maar my mood, that I have. Like my room isn't swept out now. Because I didn't feel like doing it. Things like that- it's small things.*

She also explained that mood swings are difficult and makes her feel immensely tired, so much so that her mother has to wake her up in the mornings. However, against this loss of a former, energised self, she still appears to be hopeful.

*Savanna: I would say it is difficult, but you have to take it one day at a time. One step at a time. A person can't do more than that. Because sometimes I'm so- moody that I don't- there are times that I don't want to get up. Because I'm so tired. And- and then there are times when I get up out of my own, without my mother having to- because, uhm, every day I wait for my mother to wake me up. My mother wakes me up every day. But there are times when I get up on my own, on my own. So that makes me feel better. That I can get up on my own. And I miss those times that I got up at half past five, I don't get up at that time anymore.*

If a mood episode and active-phase symptoms of schizophrenia occur together, these mood symptoms are acknowledged in a diagnosis of schizoaffective disorder (APA, 2013). The experience of mood symptoms such as unstable mood, sadness, and other depressive symptoms in individuals diagnosed with schizophrenia have also long been reported (Balci et al., 2016; see Baynes et al., 2000; Koreen et al., 1993). Gee, Pearce, and Jackson (2003) write that the psychosis experience of patients diagnosed with schizophrenia in their study include feelings such as withdrawal, tiredness, loss of motivation and energy, insomnia, suspiciousness, paranoia and hearing voices, as well as depression. The World Health Organisation found the international depression rate in schizophrenia to be between 19-81% (Balci et al., 2016) and a South African study found that the depression rate in their sample of Sesotho patients are 57% (Mosotho et al., 2011). Depression, together with many other risk factors, have also been implicated in schizophrenia as a diagnosis with a suicide risk (Balci et al., 2016; Carlborg, Winnerback, Jonsson, Jokinen, & Nordstrom, 2010; Vodusek et al., 2014). A study of the clinical presentation of schizophrenia amongst Sesotho speakers in South Africa, found a 23% degree of suicide risk amongst the participants, attributing it to the high prevalence of depressive symptoms and substance abuse (Mosotho et al., 2011). In comparing himself to his father and brother, who also suffer from schizophrenia, Leo mentioned that depression played a central role in their being sick, leading to the suicide of his father:

*Leo: I don't actually speak to people. Yes. But my family knows [of the diagnosis of schizophrenia], they know. My father didn't want treatment. He hanged himself.*

*C: SJoe, he hanged himself?*

*Leo: Yes.*

*C: Why?*

*Leo: He couldn't anymore, take the depressive.*

*C: Was he also a schizophrenia sufferer?*

*Leo: Yes. He was in the hospital once. For two weeks, I think.*

*C: Hmm. So he was in the hospital for two weeks. Okay. For?*

*Leo: Uhm, for depression.*

*C: SJoe. So he also had it in a way?*

*Leo: Yes my brother believes he suffers from depression he suffered from depression. But he doesn't want treatment, but he works and made nou another child again. Now four children now.*

*C: Your brother. So he also suffers from depression.*

*Leo: Yes but he doesn't want to admit it.*

*C: Hmm. Is it difficult?*

*Leo: Yes he also behaved strangely. Spoke strangely and blamed my mother and his wife jol and all those things.*

*C: Jol?*

*Leo: Yes has a relationship with the boss.*

*C: Okay. So he behaved strangely. And the talk strangely?*

*Leo: Yes he also said things that don't make sense.*

The association between suicidal thinking and depression and schizophrenia currently is the focus of much research in cognitive psychology, with Birchwood et al. (2000) suggesting that loss (of a former self) and entrapment (lack of control) can contribute to difficulties in social roles, relationships and autonomy. This, in turn, can lead to feelings of hopelessness, despondency, depression and even thoughts of suicide. This challenges the public misperception of people with schizophrenia as homicidal (Berzoff et al., 2011).

**Summary.** Thus far, I have highlighted participants' experiences of being different, excluded, bullied, abused, mistreated, controlled, confused, exploited, and subordinated in various ways throughout their lives. These traumatic histories of abuse and submission highlight the need to take individual histories seriously, even in people with a diagnosis of schizophrenia. I have also attempted to show how the diagnosis for the participants is associated with psychosis, but also quite powerfully with a wide range of complex emotional experiences, including fear, anxiety and paranoia, shame, anger and aggression, isolation and loneliness, and sadness. These experiences of emotional distress appear to follow an interesting cycle.

Participants in this and other studies (Vodusek et al., 2014) reacted with fear and anxiety during psychotic experiences, which manifested on the extreme end of the spectrum as paranoia (Freeman, 2007), together with the mistrust, hypersensitivity and vigilance typically associated with paranoia (Berzoff et al., 2011). Shame, of being inadequate, dysfunctional, and of being diagnosed with schizophrenia, was also prominent in the emotional profiles of the participants in this study. Another author similarly reports that patients can experience overwhelming feelings of shame and failure with being diagnosed with schizophrenia (Walsh et al., 2016). These feelings of shame are often connected to low self-esteem and internalised stigma (Flanagan et al., 2012). Gilligan (2003) writes about shame being at the root of aggression. In our study, fear, anxiety and paranoia as well as shame, often went together with anger, informing defensive and safety behaviours. On the one hand, it has been found that individuals can become aggressive or violent (Birchwood et al., 2006). On the other hand, if they experience others as threatening and unpredictable during a psychotic episode, they can enact submissive inhibition, withdrawal and avoidance of activities (Birchwood et al., 2006; Walton, 2000). In this study, anger and aggression as well as loneliness and isolation were often accompanied by feelings of sadness, moodiness and depression. For some, it even resulted in suicidal thoughts. According to Walsh et al. (2016), studies have found that these negative feelings of isolation and depression revolve around a sense of loss - lost relationships, lost resources like a home or employment, or, importantly, a loss of control (Deland et al., 2011; Kilkku et al., 2003; Williams & Collins, 1999). Some people even experience a lost chance on a normal life, experiencing themselves as less than they were (Lysaker & Lysaker, 2010). Finally, these safety and defensive behaviours have been shown to, instead of protecting the individual against a frightening environment, lead to a vicious cycle around increasingly catastrophic thinking and dysfunctional safety behaviour,

and more shame (Birchwood et al., 2006). This can pose an obstacle towards the achievement of intersubjective connections, with difficulties establishing interpersonal connections being experienced (Lysaker & Lysaker, 2010).

Simply stated, I have shown that in this as well as other studies (referenced above and briefly reviewed in Chapter 3), the diagnosis for participants is associated with psychosis, but also quite powerfully with a wide range of emotional experiences, including fear, anxiety, paranoia and shame. This fear, anxiety, paranoia and shame seemed, in turn, to lead to anger, informing defensive and safety behaviours ranging from aggression to isolation and loneliness. The pervasive sense of loss and of being less than human accompanying these experiences, often also entails feelings of sadness, moodiness and depression. A vicious cycle of fear, anxiety and paranoia, shame, anger and aggression, isolation and loneliness, sadness and more shame, anger and isolation, is thus maintained.

If Kleinman's (1988a) view that "a psychiatric diagnosis is an interpretation of a person's experience" (p. 7) is to be taken seriously, the diagnosis of schizophrenia should capture and represent the complex emotional distress as described in this and other studies. When referring to the DSM-5 (APA, 2013), these experiences are in some ways similar to the current diagnostic criteria for a diagnosis of schizophrenia, but also go beyond the DSM-5 criteria. The DSM-5 (APA, 2013) only seems to acknowledge the possible presence of a dysphoric mood (depression, anxiety, or anger) as well as a possibility of aggressive acts as associated features supporting a diagnosis of schizophrenia. Furthermore, the notion of diminished emotional expression as a negative symptom in the DSM-5 (APA, 2013), has been debated in the literature. While something must be said of the impression of apathy and indifference observed in persons diagnosed with schizophrenia, various authors argue against assuming that this emotional attenuation or blunted emotional expression indicate a lack of underlying, subjective emotional experience (Kring & Germans, 2004; Kring & Moran, 1993; Sass, 2007) - as the notion of diminished emotional expression seems to imply.

This has led studies to focus on the complex emotional experiences of people diagnosed with schizophrenia (Aghevli, Blanchard, & Horan, 2003). For example, Flanagan et al. (2012) compared the personal experience of being diagnosed with schizophrenia with the diagnostic criteria of schizophrenia in the DSM-IV-TR. They found that none of their participants reported actually experiencing a lack of emotions, but that they rather chose to not express their

emotional experiences. This was found to be due to the control of voices, confusion, to avoid social stigma and to prevent clinicians from increasing their medication. Instead, when given an opportunity, they described strong and complex emotional reactions to their symptoms, life situation and relationships: feeling sensitive, nervous, sad, disgusted, ashamed and embarrassed, scared, depressed, cursed, angry, frustrated and feeling like an outcast or alien (Flanagan et al., 2012). Therefore, it seems that there is a complexity behind the emotional distress of people diagnosed with schizophrenia, as described in these and other studies, that is not necessarily captured by a diagnosis of schizophrenia in the DSM. Following this reasoning, authors such as Hornstein (2013) advocate for the use of subjective approaches, together with the DSM-5, in order to also view “extreme states and unusual perceptions, thoughts, actions, and feelings with fresh eyes - from the perspective of the distressed person’s own categories and explanations” (p. 29).

The notion of intersubjectivity in relational psychoanalysis, or “the myth of the isolated mind” (Stolorow & Atwood, 1992, p. 9), reminds us to focus on the relational context in which emotions take place. Obscuring the complexity of emotional distress, could mean that the relational difficulties of anxious, angry, aggressive, moody, and isolated individuals are frequently attributed to internal instability, while these individuals are often reacting to a “disturbed and disturbing intersubjective fields” (Kruger et al., 2014, p. 8). In light of this, Binswanger’s (as cited in Watanabe & Kato, 2004) description of schizophrenia as a process of becoming estranged from other people is relevant, in which the establishment of relationships with others becomes difficult. Participants in this study felt afraid of others, ashamed in the presence of others, got angry and aggressive at others and isolated themselves from others. What was meant as safety and defensive behaviours, preventing the self from being further degraded in a threatening environment, often led to them further contaminating social interactions through shame behaviour (Lysaker & Lysaker, 2010).

### **Medical Discourse**

In coding the transcripts, it appeared that, despite their traumatic experiences and in contrast to their complex experience of emotional distress (as discussed above), participants, when discussing their diagnosis, quite explicitly and implicitly adhered to a medical discourse of schizophrenia. Informed by this medical model, participants constructed themselves as abnormal

and as having a dysfunctional brain, which needs to be medically treated. Also implicit in their narratives, is the diathesis-stress model.

**The abnormal person.** In the *APA Dictionary of Psychology*, “abnormal” refers to any deviation from what is considered typical, normal, usual, or healthy, particularly if the deviation is considered harmful or maladaptive; an interruption/restriction of daily life that is either distressing for others or distressing for the self (VanDenBos, 2015). DJ viewed himself as being abnormal and an outcast, in comparison to the normal, average society:

*DJ: Yes that made it difficult for me, like trying to fit in normal society. I felt like an outcast when I first came here, but as the years went by I learnt how to...cope here in Cape Town.*

*DJ: Yes I didn't feel like- I thought maybe I'm an Indian I must go back to India. Or, like...yes. You don't feel like you fit into society.*

In comparing themselves to seemingly “normal” others, individuals diagnosed with psychosis are often left with a distressing sense of abnormality and difference (Burke et al., 2016). Lisa also viewed herself as abnormal when she “went through the motions of schizophrenia”, in comparison to living a more “normal” life now in being married, going to the movies and spending time with her husband.

*Lisa: I'm like a normal person. (laughs) I feel I'm normal like a normal person, I'm living life like a normal person, it's just that I won't be able to have children and things like that. But that's just the- because of all the conditions and things like that, but I made peace with that and...my husband just be for the dogs outside (laughs). So.*

*C: So you use the word normal now. But previously?*

*Lisa: I was abnormal. (laughs)*

*C: You felt abnormal.*

*Lisa: Not normal. I felt, yes, like you, uhm, well when you're going through the motions of schizophrenia, the thoughts and things like that, you're paranoid and things like that, so you're not feeling yourself 100%. I feel like I'm living a normal life like everybody else, going to movies, spending time with my husband, got married, so that also made- he also played a role I guess. Making me feel normal and not judging me, he's very caring*



*and things like that. So he understands and he knows what to look out for if I...so...I explained to him and things like that.*

Lisa appeared to view her dysfunctional self as not her, and different from her normal, familiar self that she claimed to have regained after the psychotic symptoms improved. Lisa's words "you're not feeling yourself 100%", is similar to the ways in which people often refer to not being themselves in some cultural and symbolic way when they are sick or injured (Estroff, 1989). A sense of self-alienation or changes in the self are often reported as an essential part of the psychotic experience; something that changed, something that feels wrong and different (Deland et al., 2011; Hirschfeld et al., 2005). In response to feeling that something is wrong, several individuals experiencing psychosis then make attempts at "normalising" themselves (Catone et al., 2016). However, this can be problematic when, often in the case of chronic illness such as schizophrenia, being "not myself" is my self. Thus appears the double dilemma, in terms of the inner sense of self as well as social identity, as described by Erikson (1957):

The patient has to seek definition as acutely sick and helpless in order to achieve a measure of public validation for his illness - and simultaneously has to use all his remaining strengths to struggle against that illness - a dilemma is posed which he may resolve by simply giving up the struggle altogether and submerging himself in the sick definition permanently (p. 271).

**The dysfunctional brain.** In viewing themselves as abnormal people, participants conceptualised schizophrenia as a condition of having a dysfunctional brain, with something physically wrong in their brain, head or mind. This is a biological perspective that emphasises physiologically-based causative factors (VanDenBos, 2015).

*Eugene: I have a huge pain inside my head and it pushes onto my brains it pushes.*

*C: So it feels as if it pushes onto the brain.*

*Eugene: On the brain pushes yes and I get a huge pain inside my head and I am afraid about it, because later I will see on the brain scan- that I will be diagnosed with brain cancer. That's what I think now and so.*

*Pieter: I think it's a sickness in the head.*

*C: Hmm. Sickness in the head. Okay, can you tell me a bit more about that and how it feels for you?*

*Pieter: Uhm...I can't say nog much.*

*Jappie: Uhm...it was- I- my mind was not right man, it- I felt sick in my mind. I was feeling always sick feeling, I didn't feel right, so...uhm, feeling was not right. I couldn't take it, I got sick in my head and people was talking to me on the TV, it's almost like they talk really to me, it's almost like if you look to a photo then you- when you look to a photo and when you look to the side the eyes are looking to you. Have you seen that already? Hmm. Now it was- something about that. Yes. So I'm sick in the mind man, of schizophrenia the sickness, diagnosed. (sighs)*

*Noli: I...I think it is something disturb your mind.*

*C: Hmm. And what do you mean with disturb your mind?*

*Noli: I...maybe you not...you not see things normally. You not think normally.*

*Savanna: I know it's a, uhm, it's an chemical imbalance in my brain. That's all I know.*

*DJ: The thoughts- the worrying thoughts that run through your brain are more escalated.*

*Boom Boom: I feel there was a lot of things on my mind, but, because why. You can see I'm trying to- I wander- I tell a story and then I wander away from my story again.*

*Kloeks: It's an imbalance in the brain.*

The participants described the head, mind or the brain as not normal, sick, not right, disturbed, in pain or chemically imbalanced. The participants also described exactly how these disturbances manifest. In these descriptions of the manifestations of a dysfunctional brain, head or mind, two interesting things emerge: firstly, an image of the dysfunctional schizophrenic mind developed as fast paced, chaotic, uncontained, undisciplined, and wild - something regressed and primitive. Interestingly, Boom Boom spoke of throwing away his male brain. Traditionally, the female brain is constructed as undisciplined, mad, and emotional with the male brain constructed as rational, disciplined, and ordered (Hirschfeld et al., 2005). Hirschfeld et al.'s (2005) social constructionist study on the meaning and experience of psychosis for young men found that such gender roles can create tensions for people trying to navigate through psychosis.

*Boom Boom: I started feeling sick and started talking in a confused way. Talk about things that happened years ago. I couldn't remember anything about what happened years ago- now I can remember, but it's almost like there was a memory loss, man. It's almost like...a woman's brain works differently, a man's brain is different, but almost like I threw away that one. Forget about that forget about that, you know. And uhm...what happened was, then all those things came back to me.*

Similar to these descriptions, participants in Flanagan et al.'s (2012) study describe their experiences of disorganised speech as too much going on in their brain, having trouble sorting things out and being confused. Secondly, participants also describe the manifestation of having a dysfunctional brain as some kind of break with reality - a loss of consciousness, a state of imagination, memory loss, or sleeping.

*Jappie: Schizophrenia is about...delusional and illusional, then you get illusionate of one person. Illusionate and delusionate [neologisms], you know? Did you hear about delusionate? Schizophrenia is delusions of all people, what is sick, that is so.*

*C: So what do you- what does that mean for you? How did you delusion...ate?*

*Jappie: Uhm, for me actually now neh? It's almost like...it's almost like...you say mos verbeel- verbeeldings (imagining - imaginations). You imagine, man, that you're seeing things, ghost or so, in the reality.*

*Rudy: Uhm, it's nogal...a lot of things. My mind runs away, a wild imagination. Almost like 10 years I've been thinking about a lot of things and so. If I think must I go out, or musn't I, then I stay at home.*

*Savanna: I felt like I slept. Felt like I sleepwalked- like I walked in my sleep. It feels like that. I felt like it was one long sleep. So I don't remember my days.*

Constructing schizophrenia as having disorganised thoughts and experiencing a surreal break with reality, physically manifesting as an abnormality in a dysfunctional mind, head or brain, is very much in line with the medical model. In the medical model, the experience of psychosis takes centre stage and is defined as the experience of an abnormal mental state involving significant problems with reality testing (VanDenBos, 2015). It is characterised by serious impairments or disruptions in the most fundamental higher brain functions as manifested

in behavioural phenomena, such as delusions, hallucinations, and significantly disorganised speech (VanDenBos, 2015).

However, the use of the word “imagination” in association with psychosis is interesting - it implies creativity, playfulness and something positive. Also, Jappie uses the words “meditate, secret, clever and curious”, while Rudy speaks of “nice, good, and friendly” voices and DJ reports being “creative”.

*Jappie: I find a lot of things out, then I meditate- then I talk out and I think the secret, it is- I think in a secret. Your mind is mos a secret what you think. When you think it out...it's clever to do that man, because your mind- you must observe always when you socialise. Observe, looking here and curious also.*

*Rudy: I think it is...uhm...I think I hear voices and then...I imagine to myself. Yes. I imagine things to myself. Hear voices and so, but...if I sit and so.*

*C: Okay. And can you tell me a bit about the voices that you hear and so on?*

*Rudy: Uhm... I just hear it, I don't know, I hear it and...I just hear voices. Uhm, explain...uhm explain me...nice voices, talk nicely.*

*C: Are you saying the voices talk nicely?*

*Rudy: Yes I say, as I hear the voices, the voices tell me it sounds good, I sound good to myself, something like that.*

*C: Okay. So sometimes they are friendly?*

*Rudy: Yes they are friendly yes.*

*DJ: Sometimes you become creative like you never thought you- like say for example drawing on the computer or just having a pen you just draw something, you know.*

The word psychosis seems to originate from the Greek words for “psyche” meaning the soul and “osis” meaning abnormal condition (“Psyche,” n.d.). A psyche in mythology is said to refer to a butterfly or the soul, spirit, breath and life (“Psyche,” n.d.). As such, the original meaning of psychosis seemed to have been more positive, echoed in recent studies concluding that aspects of the psychotic experience can, at least partly, be a positive experience (Vodusek et al., 2014). Advocates of the Recovery Movement challenge the traditional notion that so-called “abnormal” symptoms associated with a diagnosis of schizophrenia are negative and should be

eliminated, arguing for the symptoms to be acknowledged and worked with (Davidson, 2003; Tomecek, 1990).

**Medical intervention.** Most participants in this study expressed positive experiences of medical treatment, associating it with physical, emotional and mental health improvement. Participants clearly deemed medication to be crucial in their path to becoming normal and “healing” what they experienced as their having a dysfunctional brain and being abnormal. DJ described being more focused and coping better after getting an injection, while Noli said that she thinks less and feels happier.

*DJ: And after when you are diagnosed and get your injection then you start to see: okay, uhm this is my illness and I can cope with it and yes I don't want to talk too much about what they are going to say, I can focus on: okay yes I need to do this to do that.*

*C: Okay, so you mentioned something about the clinic, what medication do you receive at the moment?*

*Noli: Fluanxol.*

*C: Fluanxol, okay, and how's that been for you?*

*Noli: Fine.*

*C: It's fine.*

*Noli: Hmm, I didn't notice bad thing.*

*C: Didn't notice..?*

*Noli: I didn't notice that he make bad thing to me.*

*C: Bad thing? What do you mean by that?*

*Noli: Like he...he treat me alright.*

*C: He treats you alright. Okay and how does it feel to get the injection?*

*Noli: When I get injection, I feel...I feel more...happy. Because when I- I don't know why. I think it's the injection is the best way to do it and I like it, because I- when I get it, I'm not thinking a lot.*

*C: You're not thinking a lot? What do you mean with that?*

*Noli: Like...it's like...something change when I get it.*

*C: Like how?*

*Noli: Like the voices and all of that.*

Rudy mentioned that the injection makes him feel happy, tired, drowsy, and calm.

*C: Hmm and do you want to tell me a bit about the pills that you just mentioned?*

*Rudy: Hmm, the pills are oraaait. The sleeping pill to sleep also.*

*C: Hmm okay the sleeping pills. Okay. And other medication that you receive?*

*Rudy: My injection and so.*

*C: And how does the injection feel for you?*

*Rudy: The injection feels...oraaait. I can't say, it feels...calm and so. Just feel happy. It feels- I feel tired. Tired. And drowsy.*

*C: Tired and drowsy.*

*Rudy: Yes it feels drowsy.*

*C: Is it difficult to feel like that?*

*Rudy: No uhm it's oraaait, on the one hand it is actually fairly calm. So then I'm not so up and about. Yesterday I spring cleaned a bit during the day and dusted a bit and that's what I did. That's- all that I did yesterday.*

The pills and injections are further seen as helpful and associated with feeling good, being healthy, and the absence of pain:

*C: So you feel good, it works well for you. Okay and, uhm, is there anything that you- if you think about the medication that you receive- what would you have liked to change, that maybe does not work so well?*

*Pieter: Sorry?*

*C: Is there something that you would have liked to change, something that isn't so nice?*

*Pieter: No.*

*C: So you are happy with the...with the pills?*

*Pieter: Yes.*

*C: And you said it does you good, it works nogal good. Uhm, how does the pills make you feel?*

*Pieter: It makes me feel good. Become healthy then.*

*C: Sjoe. So you feel like the pills made you healthy?*

*Pieter: Yes.*

*C: And how is your head since you use the pills?*

*Pieter: Head is oraaait, do not get headaches anymore and so.*

*C: So the headaches are also gone?*

*Pieter: Yes.*

*C: And how did the headaches feel?*

*Pieter: Is very bad. Yes.*

*Lisa: So, it depends also on you and the treatment you get in the beginning. While I would say I got good treatment when I came here that I haven't had a relapse or anything, so it was good that I came here, and they put me straight on the Fluanxol, see what dosage works for me and things like that, so I think I was very blessed to come this way- to come to Doctor De Wet and Sister Rachel and Sister Ira, they helped, the medication helped. Uhm, that was- I feel the study also helped and things like that. They are doing a good thing, that's why I try to help with other studies and things like that.*

The medication at the hand of the medical practitioner is seen as a good and blessed thing, providing focus, calmness and stability. Even though Jappie expressed dissatisfaction around inefficacy of the medical intervention, he still believes that “it's the answer is new tablets to prescribe, it is it is”. He was of the opinion that, when the medical treatments were working, the injections felt nice, provided relief and made his mind right and that the tablets healed and cured him:

*C: I'm not a doctor so I don't know about the injections, that's why I'm asking you how it felt and how was the injections for you?*

*Jappie: How it felt. It was a nice relief feeling, to feel- my mind feels right again, it is. Because they give you an injection on the bum and then it goes up to your mind, like- it just goes to your mind, man.*

*C: Okay, it almost you said it makes your mind feel...*

*Jappie: Like a nice feeling, man. It's like a....feeling that...it's like a very difficult feeling...I can't explain that feeling. (giggles)*

*C: And anything about the medication that you would've wanted to change?*

*Jappie: To prescribe new tablets.*

*C: New tablets. Why do you want new tablets? Why do you say that?*

*Jappie: What say?*

*C: Why do you need new tablets?*

*Jappie: Because some of that tablets don't work for me, it don't work for me. Not anymore. It's the answer is new tablets to prescribe, it is it is.*

*Jappie: Also the thing is with tablets, I don't feel so sick anymore like I felt sick at first. I did come right- they cured me. It healed, cured, healed.*

Similarly, even though Leo said that the medication “doesn't help that much” and that he was not adequately informed about the medical intervention, he still suggested not being stubborn when it comes to taking the medication:

*Leo: She took me to the clinic. And sat with me there. Yes.*

*C: And then what did the doctors do?*

*Leo: Then the doctor asked me questions. What day it is and...how old I am and all those things.*

*C: Hmm. And how did they explain things to you what was going on?*

*Leo: They didn't actually explain that to me.*

*C: Okay. So how did you feel, when all these things happened, but nobody explained what is actually happening?*

*Leo: They just put me on treatment.*

*C: Okay. But you didn't understand what was going on?*

*Leo: Yes, I didn't- I just took it if the treatment helps then I will use it.*

*Leo: Yes it also helps to...to get an understanding of the illness.*

*C: Hmm. And how did you go about to get an understanding?*

*Leo: I- I wasn't stubborn. I maar agreed to take the treatment. Yes think if it helps me then it helps me.*

Underlying, is a theme of the importance of the adherence to medication in order to feel calm and relaxed and having a mind that is “right”, “focused”, “not sick” and “not thinking a lot” - the opposite of schizophrenia - and eliminating abnormality, pain and illness. While participants in this study clearly thought that adherence to the medical regime is important and central to them being functional, the notion of adherence has been debated by postmodern scholars.



On the one hand, Lupton (1997) empirically argues that the medical encounter involves a negotiation of power dependent on the context of the interaction. Often for people who have experienced serious illness or hospitalisation, it is crucial to have a total reliance on and an adherence to the medical regime; trusting the power of doctors and medical interventions for providing relief from their suffering. As such, medical power as it operates in the medical encounter can be a facilitating resource within which problems are identified and dealt with (Lupton, 1997).

On the other hand, the medicalisation critique (discussed in Chapter Three) argues that this view portrays patients as mostly passive, helpless and disempowered victims against the knowledge and power of medical professionals and their medical treatments (Moncrieff, 2008). Foucault, for instance, believed that psychiatric power and knowledge about mental illness cannot be understood without reference to discipline and coercion, which are essentially used to train individuals in the society to normalise their behaviour and eliminate any abnormalities (Foucault, 1963). A more recent study shows that individuals often express a concern that their illness caused them to lose control over both their lives and their behaviours (Forchuk, Jewell, Tweedell, & Steinnagel, 2003). For some patients, lack of knowledge about their illness, combined with a lack of agency and control over their illness and the medical intervention, can result in fear, discomfort and disempowerment (Ng et al., 2008; Walton, 2000). These fears of a loss of control and being controlled by others, are often exacerbated by forced hospitalisations and medical interventions (Walsh et al., 2016). Lupton (1997) understood this as condensing patients into bodies without identities (Lupton, 1997). As drug treatment can be a particular area of conflict and debate in medical interventions (Hamann, Mendel, & Schebitz, 2010), studies advocate for the incorporation of patient knowledge, health beliefs and involvement into treatment plans to increase compliance and reduce re-hospitalisation over the long term (Hamann, Cohen, & Leucht, 2007).

**The medicated body.** Participants associated the medical intervention with being stable, calm and peaceful. Emotions and emotional lability in this discourse are deemed to be undesirable. Anger, specifically, is not seen as a good emotion to experience.

*DJ: Uhm yes I get like angry in my mind, but then I mostly just keep quiet and don't get physical or anything.*

*Eugene: I just keep myself maar calm. If people wants to argue with me dinges, then I will maar just walk away and I will try to maar just keep myself calm and then I feel nogal- and I dinges- I don't like people anymore.*

Participants in this and another study also suggested that the passivity associated with the medication can create the impression that they are lazy, tired and slow and apathetic (Flanagan et al., 2012):

*Kloeks: I sit maar in the road sister. Do maar nothing, I just sit in the road.*

*DJ: Ja they weren't- they didn't accept it because they thought: no, I 'm just lazy and don't wanna work and I and I just want to hang around and do nothing, but they didn't understand.*

Rudy mentioned above that the medication makes him feel happy, calm, tired and drowsy. Rudy's words also speak of a loss - a lost humanity ("I actually have nothing that I can do with myself") and a lost youth (referring to himself as a "little grandpa" who misses being "spoon-fed" even though he is 30 years old).

*Rudy: No it's boring- it's bad to go out, but perhaps I will meet a girl again. Do nice things, but... My mouth is a bit dry, from drinking coffee and so. But I will see as life goes on, I can't say. I don't know, I will see what I do this afternoon. Then I sit maar and drink coffee maybe, smoke a cigarette. I won't worry about my day, am going to sit maar at home. I actually have nothing to do with myself.*

*C: Is that how it feels?*

*Rudy: Yes it feels boring. I drink maar coffee, like a grandpa. A grandpa in his chair. I am getting old now.*

*C: Why do you feel like a grandpa?*

*Rudy: I almost feel like- like an old toppie, but I am still young. I got up to a lot of things when I was younger. That's why I...sit maar and think about things, and then I don't go out and I don't worry anymore I don't worry anymore. Drink at home. I know mos what it is about, so.*

*C: Good parents, okay. And your childhood times, how was that?*

*Rudy: It was wonderful, it was nice. I miss it.*

*C: You miss it, why?*

*Rudy: I was spooned since I was little.*

*C: You were?*

*Rudy: I was spooned since I was little, fed with a spoon. Always when I was little, but that was years ago, now I am older.*

*C: Hmm they don't feed you like that anymore.*

*Rudy: Ja nee. Then I scheme yes, what is going on now- not what is going on- I know. I was still little. And now I am older.*

*C: So you sometimes wish that you were still little?*

*Rudy: Yes, I didn't grow much, but okay. Maybe because I am still at home. Now I'm still there. I had a girlfriend during that time- a girlfriend. I also have a little child with her. But she and I broke up. So it still works on me, now and then I see the little child then he comes to me, but okay...its's maar so...that's maar all.*

When medical intervention happens in the context of a medical discourse that encourages the elimination of abnormality and dysfunctionality, patients are thought to be at risk of becoming “medicalised bodies”; sitting around, being seemingly passive, slow, apathetic and lazy and even losing a sense of humanity and youthfulness (Lupton, 1997). Studies show that medical treatments are sometimes presented as the only solution to emotional reactions, reporting that inpatients are frequently being sedated or told to calm down and be silent (Lorem, Frafjord, Steffensen, & Wang, 2014). Treatment is also often dispensed in the context of brief psychiatric visits, where there is little time to acknowledge and explore side effects or assess the fears, wishes, and concerns that is associated with a medical intervention (Berzoff et al., 2011). This means that some patients might not have the experience of their emotions, such as feelings of anger and loss, being validated and their histories being explored, essentially neglecting the “lived experience” of this “medicalised body” (Lupton, 1997).

**The diathesis-stress model.** Also in accordance with the medical model, Lisa clearly constructed schizophrenia as originating from “bad genes”, with stressful life circumstances such as a physical illness and studying, triggering the onset of the illness.

*Lisa: Well I was doing my in-service training, I don't know if that brought it on. And I had an abscess in my- an abscess or something and then I went for an operation for the abscess. I was normal before then the abscess and then went I went for the operation, I woke up and I was, uhm, I was having- like thinking that the nurses want to kill me and I was paranoid and things like that- I was scared in the hospital and I didn't know why. So, I was- when I woke up from the abscess I was having that. So I don't know- I was fine before then- I was stressed out because of the In Service and things like that, but when I came out of the- I don't know if the medication or the...the...putting me to sleep or if that triggered it. It wasn't mentioned or anything, but then after that when I woke up I had schizophrenia. Well then I was diagnosed- I had to go see a psychiatrist or whatever. And that is how I found out I had schizophrenia when I went to the psychologist things like that and I stayed a few days there at the- somewhere in B-Town- like a...care place where they watch you and things like that.*

*Lisa: Uhm, they say it's in the family- the genes are there. My mom says it's in my daddy's side I don't know. Yes the genes in the- my daddy's side, because his family members I don't know- his uncles or whatever- but my mom says there is uncles that have a...mental illnesses, but I don't know what mental illnesses. So I don't know if it's passed on from generation to generation. Or, it skipped a couple and came to us I don't know. Or if it's just a...stress that brought it on.*

*C: Hmm. Okay so the stress and the genes, that's mainly the things that stand out for you.*

*Lisa: Yes the stress and the genes. The genes, the family genes. So maybe the parents must be tested or, uhm, their bloods must be... (laughs) Their bloods must be detected. Not my blood, their bloods. They can see where it went wrong. (laughs) So...*

DJ, while constructing schizophrenia as an illness that physically manifests in his brain, he also thinks that relocating influenced the course of his illness:

*DJ: No I stayed with my father until I was 23...26. Yes and then uhm there was no job prospect for me in the Eastern Cape, because there's too many people looking for work and too little companies. So then I asked for my mother to move to Cape Town to stay with her and I can look for work here. But at the same time I struggled to find work here as well. So that also add, that was also one of the factors that added, that led up to me having schizophrenia also, because it was a different environment Cape Town compared to the Eastern Cape. The Eastern Cape is like subtle and surreal and you don't see any people outside and it's like quiet you know, but here in Cape Town everybody is up and about you know.*

Lisa and DJ's model of schizophrenia as a genetically predisposed illness that is triggered by stressful life circumstances are ideal examples of the diathesis-stress model. This model suggests that mental and physical disorders develop from a genetic or biological predisposition for that illness (diathesis), combined with environmental stress factors necessary for the potential risk to manifest (stress) (VanDenBos, 2015). Similarly, the stress vulnerability model maintains that psychosis results from a biological, psychological or social stressor interacting with a biological, psychological or social vulnerability. According to this model, a person with a possible biological vulnerability, like Lisa, might become ill in response to the stresses of ordinary life (Zubin & Spring, 1977). Similarly, other studies report beliefs about illness precipitants to include genetic factors where a family history of mental illness is known, combined with psychosocial stresses such as bullying, physical abuse, school-related stress and family difficulties, family life events such as illness, moving house or peer pressure (Cadario et al., 2012). In a qualitative study with Sotho-speaking patients and their caregivers in Pretoria, South Africa, illness perceptions also ranged from medical causes to social causes as contributing factors. However, even the diathesis-stress model that recognise both psychological and sociological aspects in the etiology of schizophrenia, is said by some to be essentially biomedical as the underlying genetic predisposition are deemed to be more important (Read, 2005).

**Summary.** In the previous categories, I illustrated how interviews with people carrying a diagnosis of schizophrenia suggested that such people associate a diagnosis of schizophrenia with a wide range of emotional experiences. Also, some of them linked these experiences to

different kinds of trauma: being bullied, being abused, and being controlled. Following from this, I show how it seems that, despite their traumatic experiences and complex emotional distress, participants still adhered to a medical discourse of schizophrenia. Informed by this medical model, schizophrenia is often constructed as a medical illness. This abnormality, manifesting as having a dysfunctional brain, needs to be medicalised, with a medicalised body emerging. When stress and trauma are considered within this model, it is considered in terms of a diathesis-stress model, with schizophrenia mainly caused by a genetic predisposition.

Participants therefore appeared to buy into a medical discourse and that they mostly, on a conscious level, found this interpretation of their problem to be helpful and beneficial. The reasons for their adherence to this model, which does not seem to be in line with other more complex descriptions of their emotional distress, will not be discussed in this thesis, but will be the topic of a separate paper (Hamman & Kruger, forthcoming). Participants might simply pay lip-service to the medical model, given the context within which these interviews were conducted. We will, however, suggest and show that their adherence to the model is more complex and has to do with Foucault's theorisations about the "medical gaze", "docile body" and "resistant self" (Lupton, 1997).

Medical treatments have been shown to be effective in that it helps patients to manage many of the intense emotions (Taylor & Ng, 2012). Standardised measures and operational criteria for disorders have contributed to increasing the reliability of diagnostic concepts and improving communication among researchers and clinicians (Deacon, 2013; Kirmayer et al., 2015). However, a problem arises when medical treatments and diagnostic categories act to obscure complex emotional distress, often experienced in a context of intersubjective difficulties. There is also a need to take individual histories seriously, even in people with a diagnosis of schizophrenia. Read (2005) and Baumann (2004) argue that if individuals' distress is medicalised in the format of a diagnostic category and treatment aimed at elimination of symptoms, the distress can be understood as an expression of individual dysfunction and the patients' experiences deemed irrelevant or invalid. This may serve to obscure the complexity of their emotional responses and may not best capture the psychopathology of schizophrenia. The consequences of this can include an exclusive reliance on medication as the only meaningful intervention, the minimisation of psychological dilemmas, neglecting patients' complex inner and outer worlds and that the focus of care might turn to the management of behaviours and the

treatment of symptoms, rather than to the person experiencing the diagnosis and its associated symptoms (Berzoff et al., 2011). This is why it has been said that some research on schizophrenia acts to divert attention away from the actual lived experience of individuals' psychological distress and socio-political contexts within which these individuals become "schizophrenic" (Read, 2005). Psychoanalyst Robbins (1993) writes about the possible dangers of such research and treatment:

A consequence of viewing the mental manifestations of schizophrenia as expressions of an organic disease entity separate from the personality of the sufferer, manifestations that are meaningless and incomprehensible even to the schizophrenic himself, is the direction of so-called treatment measures to expunge these with "tranquilizing" drugs and to persuade the patient to conceal his thinking, symptoms, and limitations from others and try to function as if he were normal... But the preferred "treatment" of today mirrors and enhances the schizophrenic's basic alienation from others, and, regardless of the impression conveyed by his compliance, lends reality and substance to whatever mistrustful paranoid beliefs he may have that the world is a dangerous place and that others are basically inimical to his well-being (p. 187).

## Care

Care seemed to be very prominent in how the participants understood their resilience. This care is mainly experienced as provided by families, rather than in the context of the medical model.

**Caring for others.** Participants emphasised the importance of caring for another person or thing. While Savanna's mother holds her hand (mentioned below), Savanna lovingly mentions how she holds the hand of her sister's baby:

*Savanna: But there's someone else now that- that- there's someone else who took his [deceased father's] place. Lilly- she's a baby, she's now a year old, and she took my father's place in my heart...and she's a- she is a lovely child. She's my sister's child. And I love her very much. Yes, so there where there was a place for my father, she is, she is in that place now.*

*Savanna: We play together, we walk together. I walk with her, I hold her two hands then I walk with her. And she is now learning how to walk. So it is now something that we do together.*

Rudy mentioned caring for his little animals, which is “all that he has” and Boom Boom highlights the value he places on caring for his mother.

*Rudy: And then there are little animals also, keep myself busy with the little animals.*

*C: What little animals?*

*Rudy: Like the little rabbit outside..and yes. Or the little dogs inside and the I also have a parrot, so I look after the little animals, it keeps me busy during the day. Food I give them, water...yes. It's all that I have.*

*Boom Boom: That's why I say I'm one of the good children of my mother you know, because why I take care of my mother. While I was married, I took care of my mother. Until now, you know. Then I missed one- I didn't pay them last month- late- and then I felt- I felt bad about it you know. 'Cause it's your mother, you have to take care of your mother.*

DJ also expressed a need to help others by sharing his story during the interview:

*C: And that's what helped you?*

*DJ: Yes. And it can help other people also.*

*C: Yes. I will write that up, because it seems like it is really important for you.*

*DJ: Yes it's important, it's important yes.*

*C: Okay. I think we've covered everything. I just want to check in how you're feeling after the interview?*

*DJ: I'm okay. I'm okay. Because I'm not stressed about anything I'm just open so that I can maybe think I can help someone else you know. Because I don't want them to go through what I went through, you know. Maybe self-suicide of maybe killing someone. That's not that's not on.*

De Wet (2013), in her thesis on the subjective experience of recovery in individuals diagnosed with schizophrenia in the Western Cape, highlights the role that caring plays in the



process of recovery. She cites Davidson (2003), stating that having to care for another person or thing, helps the patient work through feelings of loss by discovering aspects of themselves that they thought were lost through the illness. This can have a humanising effect on the often dehumanising and shameful diagnosis of schizophrenia and its associated symptoms, assisting in restoring a sense of identity and agency.

**Being cared for by others.** Despite sometimes feeling unloved, ashamed, isolated and alone, participants also talk of being cared for by others, a responsibility that usually falls on the primary caregiver in the family. Savanna lovingly mentioned how her mother “holds her hand” through difficult times:

*Savanna: My mother looks after me at the moment and tells me what to do. And she tells me what is right and what is wrong, so I actually only do what she tells me. She will tell me: put on your diaper, brush your hair- things like that she will tell me. Dress neatly. I can say it's almost like she holds my hand.*

Rudy and Pieter also talked of the support they receive from their father and mother:

*Rudy: A lot, he [father] helps me a lot.*

*C: What does he do for you?*

*Rudy: He does what I ask him to do. Like...I will ask him...*

*C: Like what things does he do for you?*

*Rudy: He sits and- ag I sit and if I nou would like a beer, or cigarette, then he buys me a beer or a cigarette.*

*C: And, uhm, that time, who was the important people in your life?*

*Pieter: Was my mother.*

*C: Okay. Tell me a bit about her?*

*Pieter: She cares about us. Anything that we ask her, she gives to us.*

Lisa seemed to be different and special in a good way, being spoiled by and being the focus of her father:

*Lisa: Uhm we got a good relationship, we speak openly, uhm...understanding. I have more a relationship with my daddy, I'm more close with my daddy. I'm daddy's girl, like*

*they all say I'm spoiled from my daddy. Whatever I want, then daddy is there. I've always been that, my sisters always say I'm the spoiled one. (laughs) I guess it's because I got all the conditions and I was the focus. Always sick and things like that, always some episode with me. We got more close- my mom is more close to my sister- they have- although she says she loves us all the same, no favourites, but... We speak, I love them.*

In this and other studies (Chan, 2011; De Wet, 2013; Molefi, 2009), caring for an individual diagnosed with schizophrenia is often done by family members (Chan, 2011; Molefi, 2009; Mosotho et al., 2011). In this study, family members are described as being helpful, supportive, understanding, present and dependable. The importance of extending this context of care to the medical environment has been stressed by Kirmayer (1988), urging medical professionals to deliver health care in a way that cultivates empathy by exploring meanings of distress and recognising the person behind the diagnosis. Berzoff (2011) argues that this “empathic hearing” includes “attending to the content of psychotic processes recognising that it may be internally rational and logical to the patient” (p. 309).

**Summary.** Despite their traumatic experiences and in contrast to their complex experience of emotional distress, participants when discussing their diagnosis, quite explicitly and implicitly adhered to a medical discourse of schizophrenia that they mostly, on a conscious level, find to be helpful and beneficial. In their understanding of resilience, care seemed to be very prominent. This care is mainly provided by families, rather than in the context of the medical model.

In order to recognise the suffering behind the distress in a way that is caring and humanising, new conceptualisations of a diagnosis of schizophrenia also incorporate a psychological and subjective perspective on the pathogenesis of schizophrenia. For example, Garrett and Turkington (2011) propose an integrated model combining cognitive behavioural approaches to psychosis with psychodynamic psychotherapy. This is done in order to broaden the theoretical understanding of the pathogenesis of schizophrenia as well as improve treatment. Psychodynamic skills are seen as essential in extended treatments where the patient's self can be nurtured over time by “bearing empathic witness to the patient's existence as a person” (Lysaker & Lysaker, 2008, p. 11). Psychoanalytic object relations theory is also argued to be useful in understanding the unconscious meaning of delusions and hallucinations, stressors and trauma,

and how self-esteem is regulated (Klein, 1935); paying attention to that which gives the symptom its origin and power. This essentially provides a frame which lends depth of emotional understanding, tact, and timing to the treatment process of individuals diagnosed with psychosis. This is combined with a cognitive behavioural technique that initiates treatment by working with returning so-called “thing representations” of mental life to the boundary of the self, i.e. returning the conscious experience of psychotic symptoms as an event in the outside world, to the inner world of thoughts and feelings (Garrett & Turkington, 2011).

Working with and showing that subjective and psychological aspects of the psychotic experience can carry great subjective significance for patients (Vodusek et al., 2014) and are not fundamentally different from the experience of common humanity, might be a way of humanising the psychopathology of schizophrenia. As such, new and integrative conceptualisations of the diagnosis of schizophrenia and its associated symptoms challenge the disease model of a “pathological otherness” (Baumann, 2004). Such integrated models are argued by some to be an integral and critical component of managing schizophrenia in a clinical setting, informing and humanising treatment so that it might truly become systems of care (Baumann, 2004; Charles & O’Loughlin, 2012; Garrett & Turkington, 2011).

### **Conclusion**

In this chapter, social constructionist grounded theory was used to describe and make sense of the raw data that was collected by means of a semi-structured interview schedule about how people diagnosed with schizophrenia experience and understand their psychological distress and the subsequent diagnosis. A number of categories were presented in relation to the existing and relevant literature. This included discussions about the participants’ historical selves and complex emotional worlds as well as the underlying medical discourse and the importance that is placed on care. A comprehensive summary of these findings can be found in the following, final chapter of this study.

Recently, South African-based psychiatrist Sean Baumann compiled a cantata (a piece of music written for voice or voices and instruments) named *Madness: Songs of Hope and Despair*. In an interview about this cantata, he talks of the “skoonheid en verskrikking van waansin” (beauty and terror of madness) that he has witnessed in patients struggling with a diagnosis of schizophrenia (La Vita, 2016). The reasons that he gives for compiling this music piece encapsulate my arguments in this chapter. He refers to how psychotic experiences often embody

feelings of inadequacy, shame, alienation and suffering - often inadequately captured by diagnostic concepts. He discusses how he has set out to tell the stories of patients diagnosed with schizophrenia, who are struggling with something difficult and frightening, in order to challenge the misrepresentation of people diagnosed with severe mental illnesses. He ends by saying that this forms part of the therapeutic process.

*Die idee het deels ontspring uit 'n soort ontsteltenis oor die wanvoorstelling van ernstige geestesiektes en die oortuiging dat daardie soort wanvoorstelling bydra tot uitsluiting en lyding... Hul stories moet vertel word; ek wil in 'n sin voorspraak maak vir mense wat in hierdie vreemde wêreld leef, en die boodskap oordra dat hulle worstel met iets wat werklik enorm en moeilik en skrikwekkend is. En om dit net af te maak as psigoties of geestesiektes, is nie voldoende nie... Ook om hul uitsluiting te verminder en die algemene beskouing dat dit iets is om oor skaam te wees, of dat dit die een of ander gebrokenheid verteenwoordig, te verander. 'n Deel van daardie poging is om hierdie stories te vertel. Dit is my pasiënte se stories in hul eie woorde... Dis vreemd en verskriklik, maar dit is wat met hulle gebeur en ons kan dit nie geringskat nie; ons moet daarop ag slaan. Dit is deel van die terapeutiese proses.* [The idea partly originated from a kind of dissatisfaction with the misrepresentation of serious mental illness and the belief that that kind of misrepresentation contributes to exclusion and suffering... Their stories must be told; I want to in a sense advocate for people living in these strange worlds, and convey the message that they struggle with something that is really huge and difficult and frightening. And to just label it as psychotic or mental illness is not sufficient... Also to reduce their exclusion and to change the general perception that it is something to be ashamed of or that it is representative of some sort of brokenness. A part of that effort is to tell these stories. This is my patients' stories in their own words... It is strange and terrible, but that is what happened to them and we cannot underestimate it; we must pay attention to it. It is part of the therapeutic process.] (cited in La Vita, 2016, paras. 1–5)

## CHAPTER SIX: CONCLUSION

### Aim and Objectives of the Study

Firstly, epidemiological research highlights the severity of the symptoms and outcomes associated with a diagnosis of schizophrenia, the burden of which is increasing substantially, together with other chronic non-communicable diseases, in many low- and middle-income countries such as South Africa (Lund et al., 2010, 2012, Mayosi et al., 2009, 2012). Secondly, numerous scholars have been critical of the existing research on schizophrenia, claiming that, despite the proliferation in quantitative studies, it is unclear to what extent current research has achieved a sophisticated and comprehensive understanding of the emotional distress of individuals diagnosed with schizophrenia and how they make meaning of their distress (Baumann, 2010; Davidson, 2003; Estroff, 2004; Geekie et al., 2012; Geekie & Read, 2009; Walsh et al., 2016). The relevance of diagnostic categories such as schizophrenia, specifically in the developing world, has also been questioned. Thirdly, on recognising the suffering behind this diagnosis, new conceptualisations of a diagnosis of schizophrenia have suggested the importance of also incorporating a psychological and subjective perspective on the pathogenesis of schizophrenia, especially in developing countries, while acknowledging the biological underpinnings (Baumann, 2004, 2010; Garrett & Turkington, 2011; Robbins, 1993).

The main aim of the current study was therefore to investigate and develop a deeper and richer understanding of the subjective experience of a diagnosis of schizophrenia in South Africa. In order to achieve this aim, the following objectives were pursued: (1) to explore how a group of individuals from the Western Cape, South Africa, subjectively experience the diagnosis of schizophrenia and the associated symptoms; and (2) to investigate how this group of individuals make sense of, or understand, the diagnosis of schizophrenia and the symptoms associated with it. In other words, how do these individuals themselves describe and construct their emotional distress and its associated symptoms?

This aim and objectives were attained with the use of in-depth, individual interviews utilising semi-structured interview schedules. These interviews focused on how a sample of twelve individuals diagnosed with schizophrenia and living in the Western Cape, South Africa, experience and understand a diagnosis of schizophrenia and its associated symptoms. Each interview was audio-recorded and transcribed verbatim. Data was analysed with the use of social

constructionist grounded theory, with interpretations informed by relational psychoanalysis and social theory. This method of data analysis is consistent with the social constructionist theoretical perspective on which this study is based.

### **Summary of Findings**

The main categories that arose from the data on the experiences and understandings of a diagnosis of schizophrenia and its associated symptoms of a group of individuals from the Western Cape, South Africa, were as follows: historical selves, complex emotional worlds, medical discourse, and care.

Interviews with these individuals revealed diverse and difficult stories of being hurt in various ways throughout their lives. Current research increasingly acknowledges the need to recognise and respond to environmental risk factors and life course events that may adversely affect symptoms, the potential for recovery, and quality of life in people diagnosed with schizophrenia, specifically traumatic victimisation experiences during childhood and adulthood (Bebbington et al., 2004; Burns et al., 2011; Charles & O'Loughlin, 2012; Morgan et al., 2016; Read, 2005; Trotta et al., 2013; Williams & Collins, 1999). These traumatic histories of abuse and submission highlight the need to take individual histories seriously, even in people with a diagnosis of schizophrenia.

The interviews further suggested that while all of the participants clearly had psychotic experiences, they also experienced rich and diverse emotional worlds often in reaction to disturbed and disturbing intersubjective fields (Baumann, 2004; Bradfield & Knight, 2008). A complex and vicious cycle of fear, anxiety and paranoia; shame, anger and aggression; loneliness and isolation; sadness, and even more shame, emerges - not necessarily captured by the diagnosis of schizophrenia.

Thirdly, it appeared that, despite their traumatic experiences, and in contrast to their complex experience of emotional distress, participants, when discussing their diagnosis, quite explicitly and implicitly adhered to a medical discourse of schizophrenia. Informed by this medical model, participants constructed themselves as abnormal and as having a dysfunctional brain, which needs to be medically treated.

Lastly, in participants' understandings of resilience, caring for others and being cared for by others seemed to be very important for restoring a sense of humanity (Davidson, 2003; De Wet, 2013). This care was mainly provided by families, rather than in the context of the medical

model. Despite the fact that the diagnosis is helpful and facilitates the medical treatment of the person, it can also obscure some of the very complex emotional experiences of some very traumatised, scared, ashamed, angry, lonely and sad individuals who carry the diagnosis. This often entails that these people are not dealt with as complex human beings who have been hurt and also leads to them not defining themselves as such. Integrated models are suggested to recognise the suffering behind this diagnosis; these models include subjective and psychological perspectives on the pathogenesis of schizophrenia that promise a caring and humanising approach in a clinical setting (Baumann, 2004; Garrett & Turkington, 2011). While each treatment of each patient will be different, the stance will always have to be the same: one of curiosity and loving attentiveness (Kruger, 2015). This will involve paying attention to “the chronicles of unrecognition, fear, danger, capture, sense torture, annihilation, and indignant anger”, because “these are the accounts of trauma, persistence, and courage of people with schizophrenia...they are the voices of survival, healing, gratitude, reconstitution, and everyday life of people who struggle with symptoms of treatment as well as symptoms of illness” (Estroff, 2004, p. 285).

### **Limitations of the Study**

This study was conducted with a small sample at a specific research unit in a specific context at a specific point in time. While this is consistent with the qualitative research design, informed by social constructionism, this means that the range of experiences represented are not generalisable to the greater population of individuals diagnosed with schizophrenia. However, these findings might still be relevant in other contexts. The findings suggest that it is important to investigate, in all contexts, traumatic life histories and emotional experiences, often disrupting social connections, in people diagnosed with schizophrenia. This is because these aspects might in general be neglected and not adequately captured in a diagnosis of schizophrenia.

It also seems clear that all individuals experiencing schizophrenia are not necessarily infused with the emotional responses and traumatic histories in identical ways. Given the scope of this thesis, little attention was paid to very important individual differences amongst participants (such as gender, race and class). The personalities and histories of participants were briefly described, but there was not a detailed analysis of how these personalities and histories impacted on specific illness experiences.

Another limitation of this study was that it was located at a research unit where participants previously participated in other research studies. While the sample was quite diverse in terms of gender and age, this might have caused the sample to be particularly medicalised. I also got the impression that, in asking certain questions, participants associated me with the medical professionals at the research unit and felt the need to express their gratitude towards the professionals at the research unit in fear of portraying the image that the research unit was not helpful.

Also, all the participants in the sample spoke either Afrikaans or English. While this limited the diversity of the sample, this criterion was set initially to enable me to conduct the interviews myself and be aware of more subtle nuances in the use of language. Therefore, future research should include other groups of individuals, perhaps with less exposure to the medical regime, within the broader South African context, specifically non-English and Afrikaans-speaking individuals from different socioeconomic, racial and cultural groups.

Also, while the social constructionist theoretical framework of this study acknowledges the influence of subjectivity and intersubjectivity, it is possible that other researchers would have identified other categories from the data. While it is recognised that my own subjectivity as researcher affected every stage of the research process, it is a limitation of this study that its scope did not allow for a more detailed investigation of exactly how my subjectivity impacted on all aspects of the research process.

Furthermore, in terms of the research process, I found the transcription of the audio recordings limiting in that it is possible that important nonverbal communication, energy, and dynamics from the interviews were lost in the transcriptions. It could be beneficial for future studies to include video recordings when conducting such interviews.

### **Implications of the Study and More Recommendations**

The knowledge that was gained through this research can only be considered useful if it can benefit people like the research participants by informing future research, policy and mental health practices.

### **Working Towards New Understandings of the Diagnosis of Schizophrenia**

This study was, in the first instance, descriptive in that it provided a detailed description of the subjective experiences of individuals diagnosed with schizophrenia in the South Africa context. It is



argued above that such a description is crucial and lacking in the local literature. Secondly, the study can make a significant contribution in providing documentation on the manifestation of schizophrenia in the specific context of the Western Cape, South Africa. Thirdly, the study attempted to raise awareness for and make individuals diagnosed with schizophrenia and their diverse experiences of this diagnosis visible within scientific literature. This study also makes a significant contribution to the development of theory pertaining to the psychological experiences of South African individuals diagnosed with schizophrenia and the psychology of schizophrenia in general.

It is hoped that this can contribute toward also incorporating a psychological and subjective perspective on the pathogenesis of schizophrenia, specifically in the context of a developing country like South Africa. This research might guide new understandings without obscuring the subjectivity of those who need help. This might be a way to de-pathologise the position of the individual diagnosed with schizophrenia to an extent (Charles & O'Loughlin, 2012). As a Dutch social psychiatrist Marius Romme claims, perhaps some people diagnosed as suffering from severe mental illness are more in need of liberation than of cure (Romme & Escher, 1993).

### **Interventions/Treatments**

Integrated models are argued by some to be an integral and critical component in managing schizophrenia in a clinical setting (Baumann, 2004, 2010; Garrett & Turkington, 2011; Robbins, 1993). For instance, it has been shown that international treatment programmes that are the most effective for individuals struggling with a diagnosis of schizophrenia, include isolation and difficulties in the achievement of intersubjectivity in the symptom picture and recognise the importance of human connections by including it in the treatment model (Charles & O'Loughlin, 2012). Morgan et al. (2016) suggest targeting social cognitive deficits associated with a diagnosis of schizophrenia in order to reduce a vulnerability to victimisation by assisting individuals to adopt self-protective behaviours and effectively handle threatening situations. In doing so, these individuals can develop their own agency and use it to recover their life and humanity outside of the diagnosis (Davidson, 2003).

In a South African context, the traditional Western psychiatric belief that no meaning is attached to symptoms and that treatment should be aimed at elimination of symptoms, contrasts with other belief systems or cultures where psychotic symptoms are invested with social meanings and influenced by tradition (Baumann, 2004). For example, hearing voices might become listening to ancestors and in this way is transformed from a pathological symptom to a

more validating experience. In this study, psychotic symptoms seemed to be personally meaningful and were even sometimes described as including positive aspects. The socially-constructed meanings of psychotic experiences are then said to play an important role in how the treatment of a diagnosis of schizophrenia is to be understood (Baumann, 2004).

Overall, the findings of the current study is in agreement with contemporary trends in schizophrenia research that if treatment is to be effective, it should also be concerned with prevention, with the context and meaning of the illness as well as intervention and with care as well as cure (Charles & O'Loughlin, 2012).

### **Future Research on Schizophrenia**

A large portion of the published studies on schizophrenia in South Africa are quantitative in nature (Read et al., 2015). What is needed is a deeper understanding of a diagnosis of schizophrenia. The findings discussed in this study show that a wide range of interpersonal, social and emotional issues affect individuals' experiences and meanings of a diagnosis of schizophrenia. This highlights the importance of using theoretical perspectives and research methodologies that pay attention to multi-layered, complex psychological experiences of schizophrenia. Therefore, future studies can focus on:

- Respecting individuals' own accounts of their experiences as a source of information, without assuming "expert" knowledge on the subject;
- Conducting research from social constructionist, phenomenological or feminist perspectives on the topic of schizophrenia, so that we can increase our understanding of unique experiences of diagnoses in specific social and cultural contexts;
- The treatment/prevention of schizophrenia; the impact of social/political conditions; and the effectiveness of existing treatment interventions;
- Including other groups of individuals within the broader South African context, such as non-English and Afrikaans-speaking South African individuals, individuals from different regions, as well as individuals from different socioeconomic, racial and cultural groups;
- Researcher transparency and reflexivity that should become a standard in order to facilitate responsible and critical engagement with researchers' own power and subjective perceptions inherent to their research;
- How individual differences amongst participants (such as gender, race and class) impact

on specific illness experiences. Individual case studies will constitute a very important follow-up project.

## REFERENCES

- Adler, G. (1978). The psychotherapy of schizophrenia: Semrad's contributions to current psychoanalytic concepts. *Schizophrenia Bulletin*, 5(1), 11–137. doi:10.1093/schbul/5.1.130
- Aghevli, M. A., Blanchard, J. J., & Horan, W. P. (2003). The expression and experience of emotion in schizophrenia: A study of social interactions. *Psychiatry Research*, 119(3), 261–270. doi:10.1016/S0165-1781(03)00133-1
- Ahern, L., & Fisher, D. (2001). Recovery at your own pace. *Journal of Psychosocial Nursing and Mental Health Services*, 39(4), 22–33. doi:10.3928/0279-3695-20010401-11
- Andreasen, N. C. (1984). *The broken brain: The biological revolution in psychiatry*. New York: Harper and Row.
- Andreasen, N. C. (1997). The evolving concept of schizophrenia: From Kraepelin to present and future. *Schizophrenia Research*, 28, 105–109. doi:10.1016/S0920-9964(97)00112-6
- Andreasen, N. C. (2007). DSM and the death of phenomenology in America: An example of unintended consequences. *Schizophrenia Bulletin*, 33, 108–112. doi:10.1093/schbul/sbl054
- Andrews, T. (2012). What is social constructionism. *The Grounded Theory Review*, 11(1). Retrieved from <http://groundedtheoryreview.com/2012/06/01/what-is-social-constructionism/>
- APA. (1980). *Diagnostic and statistical manual of mental disorders: DSM-III*. Washington: American Psychiatric Association.
- APA. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington: American Psychiatric Association.
- Asmal, L., Mall, S., Kritzinger, J., Chiliza, B., Emsley, R., & Swartz, L. (2011). Family therapy for schizophrenia: Cultural challenges and implementation barriers in the South African context. *African Journal of Psychiatry*, 14, 367–371. doi:10.4314/ajpsy.v14i5.3

- Balaji, M., Chatterjee, S., Koschorke, M., Rangaswamy, T., Chavan, A., Dabholkar, H., ... Thornicroft, G. (2012). The development of a lay health worker delivered collaborative community based intervention for people with schizophrenia in India. *BMC Health Services Research*, 12(1), 1. doi:10.1186/1472-6963-12-42
- Balci, G., Oter, G., Akdag, H., Bekki, A., Kisa, C., & Goka, E. (2016). Factors associated with depression in patients with schizophrenia. *Journal of Mood Disorders*, 6(2), 54–62. doi:10.5455/jmood.20160328052653
- Baumann, S. E. (2004). Do elephants suffer from schizophrenia? (or do the schizophrenias represent a disorder of self-consciousness?) A Southern African perspective. Presented at the 13th National Congress of the South African Society of Psychiatrists, Drakensberg, South Africa. Retrieved from <http://sajp.org.za/index.php/sajp/article/viewFile/150/141>
- Baumann, S. E. (2010). The problematic neglect of phenomenology in contemporary psychiatry. *South African Journal of Psychiatry*, 16(4), 279. Retrieved from [https://scholar.google.co.za/scholar?hl=en&q=Baumann%2C+S.+E.+%282010%29.+The+problematic+neglect+of+phenomenology+in+contemporary+psychiatry.+South+African+Journal+of+Psychiatry%2C+16%284%29%2C+279.&btnG=&as\\_sdt=1%2C5&as\\_sdtpr=](https://scholar.google.co.za/scholar?hl=en&q=Baumann%2C+S.+E.+%282010%29.+The+problematic+neglect+of+phenomenology+in+contemporary+psychiatry.+South+African+Journal+of+Psychiatry%2C+16%284%29%2C+279.&btnG=&as_sdt=1%2C5&as_sdtpr=)
- Baumann, S. E. (Ed.). (2015). *Primary care psychiatry: A practical guide for southern Africa* (2nd ed.). Cape Town: Juta & Company.
- Baynes, D., Mulholland, C., Cooper, S. J., Montgomery, R. C., MacFlynn, G., & Lynch, G. (2000). Depressive symptoms in stable chronic schizophrenia: Prevalence and relationship to psychopathology and treatment. *Schizophrenia Research*, 45, 47–56. doi:10.1016/S0920-9964(99)00205-4

- Bebbington, P. E., Bhugra, D., Brugha, T., Singleton, N., Farrell, M., Jenkins, R., ... Meltzer, H. (2004). Psychosis, victimisation and childhood disadvantage. *The British Journal of Psychiatry*, 185(3), 220–226. doi:10.1192/bjp.185.3.220
- Bechdolf, A., Thompson, A., Nelson, B., Cotton, S., Simmons, M. B., & Amminger, G. P. (2010). Experience of trauma and conversion to psychosis in an ultra-high risk (prodromal) group. *Acta Psychiatrica Scandinavica*, 121(5), 377–384. doi:10.1111/j.1600-0447.2010.01542.x
- Bell, L. V. (1991). *Mental and social disorder in sub-Saharan Africa: The case of Sierra Leone, 1787-1990*. New York: Greenwood.
- Bentall, R. P. (2004). Abandoning the concept of schizophrenia: The cognitive psychology of hallucinations and delusions. In J. Read, L. R. Mosher, & R. P. Bentall (Eds.), *Models of madness: Psychological, social and biological approaches to schizophrenia*. Hove: Brunner-Routledge.
- Bentall, R. P., Jackson, H. F., & Pilgrim, D. (1988). Abandoning the concept of schizophrenia: Some implications of validity arguments for psychological research in psychotic phenomena. *British Journal of Clinical Psychology*, 27, 303–324. doi:10.1111/j.2044-8260.1988.tb00795.x
- Berzoff, J., Flanagan, L. M., & Hertz, P. (Eds.). (2011). *Inside out and outside in: Psychodynamic clinical theory and psychopathology in contemporary multicultural contexts* (3rd ed.). Lanham: Rowman & Littlefield Publishers.
- Birchwood, M. (2003). Pathways to emotional dysfunction in first-episode psychosis. *The British Journal of Psychiatry*, 182(5), 373–375. doi:10.1192/bjp.182.5.373
- Birchwood, M., Meaden, A., Trower, P., Gilbert, P., & Plaistow, J. (2000). The power and omnipotence of voices: Subordination and entrapment by voices and significant others. *Psychological Medicine*, 30(2), 337–344. doi:10.1017/S0033291799001828

- Birchwood, M., Trower, P., Brunet, K., Gilbert, P., Iqbal, Z., & Jackson, C. (2006). Social anxiety and the shame of psychosis: A study in first episode psychosis. *Behaviour Research and Therapy*, 45(5), 1025–1037. doi:10.1016/j.brat.2006.07.011
- Bishop, M. (2014). *Resilience in families in which a member has been diagnosed with schizophrenia* (Master's thesis). Stellenbosch University, Stellenbosch, South Africa.
- Blankenburg, W. (2001). First steps towards a psychiatry of “common sense.” *Philosophy, Psychiatry and Psychology*, 8, 303–315. doi:10.1353/ppp.2002.0014
- Bless, C., Higson-Smith, C., & Sithole, S. L. (2001). *Fundamentals of social research methods: An African perspective* (5th ed.). Cape Town: Juta.
- Bloom, F. E. (1993). Advancing a neurodevelopmental origin for schizophrenia. *Archives of General Psychiatry*, 50(3), 224–227. doi:10.1001/archpsyc.1993.01820150074008
- Boss, M. (1979). *Existential foundations of medicine and psychology*. New York: Jason Aronson.
- Botha, U. A., Koen, L., & Niehaus, D. J. H. (2006). Perceptions of a South African schizophrenia population with regards to community attitudes towards their illness. *Social Psychiatry and Psychiatric Epidemiology*, 41(8), 619–623. doi:10.1007/s00127-006-0071-1
- Boydell, K. M., Stasiulis, E., Volpe, T., & Gladstone, B. (2010). A descriptive review of qualitative studies in first episode psychosis. *Early Intervention in Psychiatry*, 4, 7–24. doi:10.1111/j.1751-7893.2009.00154
- Boyle, M. (1999). Diagnosis. In C. Newnes, G. Homes, & C. Dunn (Eds.), *This is madness: A critical look at psychiatry and the future of mental health services*. Ross-on-Wye: PCC Books.
- Bradfield, B. C., & Knight, Z. G. (2008). Intersubjectivity and the schizophrenic experience: A hermeneutic phenomenological exploration. *South African Journal of Psychology*, 38(1–2), 33.
- Retrieved from

[https://scholar.google.co.za/scholar?q=Bradfield%2C+B.+C.%2C+%26+Knight%2C+Z.+G.+%282008%29.+Intersubjectivity+and+the+schizophrenic+experience%3A+A+hermeneutic+phenomenological+exploration.+South+African+Journal+of+Psychology%2C+38%281%E2%80%9332%29%2C+33.&btnG=&hl=en&as\\_sdt=0%2C5](https://scholar.google.co.za/scholar?q=Bradfield%2C+B.+C.%2C+%26+Knight%2C+Z.+G.+%282008%29.+Intersubjectivity+and+the+schizophrenic+experience%3A+A+hermeneutic+phenomenological+exploration.+South+African+Journal+of+Psychology%2C+38%281%E2%80%9332%29%2C+33.&btnG=&hl=en&as_sdt=0%2C5)

- Brooke-Sumner, C., Petersen, I., Asher, L., Mall, S., Egbe, C. O., & Lund, C. (2015). Systematic review of feasibility and acceptability of psychosocial interventions for schizophrenia in low and middle income countries. *BMC Psychiatry*, *15*(1). doi:10.1186/s12888-015-0400-6
- Brown, C., & Lloyd, K. (2001). Qualitative methods in psychiatric research. *Advice on Psychiatry Treatment*, *7*, 350–360. doi:10.1192/apt.7.5.350
- Buchanan, R. W., & Carpenter, W. T. (1994). Domains of psychopathology: An approach to the reduction of heterogeneity in schizophrenia. *Journal of Nervous & Mental Disease*, *182*(4). Retrieved from [http://journals.lww.com/jonmd/Abstract/1994/04000/Domains\\_of\\_Psychopathology\\_\\_An\\_Approach\\_to\\_the](http://journals.lww.com/jonmd/Abstract/1994/04000/Domains_of_Psychopathology__An_Approach_to_the)
- Burke, E., Wood, L., Zabel, E., Clark, A., & Morrison, A. P. (2016). Experiences of stigma in psychosis: A qualitative analysis of service users' perspectives. *Psychosis*, *8*(2), 130–142. doi:10.1080/17522439.2015.1115541
- Burns, J. K., Jhazbhay, K., Esterhuizen, T., & Emsley, R. (2011). Exposure to trauma and the clinical presentation of first-episode psychosis in South Africa. *Journal of Psychiatric Research*, *45*(2), 179–184. doi:10.1016/j.jpsychires.2010.05.014
- Burr, V. (2003). *An introduction to social constructionism*. London, UK: Routledge.



- Cadario, E., Stanton, J., Nicholls, P., Crengle, S., Wouldes, T., Gillard, M., & Merry, S. N. (2012). A qualitative investigation of first-episode psychosis in adolescents. *Clinical Child Psychology and Psychiatry*, 17(1), 81–102. doi:10.1177/1359104510391860
- Carey, B. (2011, October 3). Talk therapy lifts severe schizophrenics. *The New York Times*. New York. Retrieved from <http://www.nytimes.com/2011/10/04/health/research/04schiz.html?action=click&contentCollection=Health&module=RelatedCoverage&region=Marginalia&pgtype=article>
- Carey, B. (2015a, October 20). New approach advised to treat schizophrenia. *The New York Times*. San Francisco. Retrieved from <http://www.nytimes.com/2015/10/20/health/talk-therapy-found-to-ease-schizophrenia.html?action=click&contentCollection=Health&module=RelatedCoverage&region=EndOfArticle&pgtype=article>
- Carey, B. (2015b, December 28). Programs expand schizophrenic patient's role in their own care. *The New York Times*. San Francisco. Retrieved from [http://www.nytimes.com/2015/12/29/health/programs-expand-schizophrenic-patients-role-in-their-own-care.html?\\_r=0](http://www.nytimes.com/2015/12/29/health/programs-expand-schizophrenic-patients-role-in-their-own-care.html?_r=0)
- Carey, B. (2016, January 27). Scientists move closer to understanding schizophrenia's cause. *The New York Times*. New York. Retrieved from <http://www.nytimes.com/2016/01/28/health/schizophrenia-cause-synaptic-pruning-brain-psychiatry.html>
- Carlborg, A., Winnerback, K., Jonsson, E. G., Jokinen, J., & Nordstrom, P. (2010). Suicide in schizophrenia. *Expert Review of Neurotherapists*, 10, 1153–1164. doi:10.1586/ern.10.82

- Catone, G., Pisano, S., Broome, M., Lindau, J. F., Pascotto, A., & Gritti, A. (2016). Continuity between stressful experiences and delusion content in adolescents with psychotic disorders - A pilot study. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology*, 4(1), 14–22. Retrieved from <http://www.sjcapp.org/index.php/sjcapp/article/view/20362/20174?acceptCookies=1>
- Chadwick, P., Birchwood, M., & Trower, P. (1996). *Cognitive therapy for delusions, voices and paranoia*. Chichester: John Wiley & Sons.
- Chan, S. W. (2011). Global perspective of burden of family caregivers for persons with schizophrenia. *Archive of Psychiatry Nursing*, 25, 339–349. doi:10.1016/j.apnu.2011.03.008
- Charles, M., & O’Loughlin, M. (2012). The complex subject of psychosis. *Psychoanalysis, Culture & Society*, 17(S4), 410–421. doi:10.1057/pcs.2012.30
- Charmaz, K. (1995). Grounded theory. In J. A. Smith, R. Harre, & L. Van Langenhove (Eds.), *Rethinking Methods in Psychology* (pp. 27–49). London: Sage Publications.
- Charmaz, K. (2000). Grounded Theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509–535). London: Sage Publications.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage Publications.
- Charmaz, K. (2008). Constructionism and the grounded theory. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of Constructionist Research*. New York: The Guilford Press.
- Chase, S. E. (2005). Narrative inquiry. In N. K. Denzin & Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 651–679). Thousand Oaks: Sage Publications.
- Chesler, P. (1972). *Women and madness*. New York: Doubleday.

- Chiliza, B. (2015). *A prospective study of clinical, biological and functional aspects of outcome in first episode psychosis* (Doctoral dissertation). Stellenbosch University, Stellenbosch.
- Christou, H. (2013). *Die bleek man op my hakke: My lewe met skisofrenie*. Cape Town: Tafelberg.
- Cohen, A., Patel, V., Thara, R., & Guereje, O. (2008). Questioning an axiom: Better prognosis for schizophrenia in the developing world? *Schizophrenia Bulletin*, 34(2), 229–244.  
doi:10.1093/schbul/sbm105
- Cohen, B. M. Z. (2008). *Mental health user narratives: New perspectives on illness and recovery*. London: Palgrave Macmillan.
- Cooper, D. G. (1967). *Psychiatry and anti-psychiatry*. London: Paladin.
- Corin, E., Thara, R., & Padmavati, R. (2004). Living through the staggering world: The play of signifiers in early psychosis in South India. In J. H. Jenkins & R. J. Barrett (Eds.), *Schizophrenia, culture, and subjectivity: The edge of experience*. Cambridge: Cambridge University Press.
- Davidson, L. (1992). Developing an empirical–phenomenological approach to schizophrenia research. *Journal of Phenomenological Psychology*, 23(1), 3–15. doi:10.1163/156916292X00018
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York: New York University Press.
- Davis, L. (2002). *Bending over backwards: Disability, dismodernism, and other difficult positions*. New York: NYU Press.
- Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review*, 33(7), 846–861.  
doi:10.1016/j.cpr.2012.09.007

- De Vos, A. S., Strydom, H., Fouche, C. B., & Delpont, C. S. L. (2005). *Research at grass roots: For the social sciences and human service professions* (3rd ed.). Pretoria: Van Schaik Publishers.
- De Wet, A. (2013). *Hearing their voices: The lived experience of recovery from first-episode psychosis in schizophrenia* (Master's thesis). Stellenbosch University, Stellenbosch, South Africa.
- De Wet, A., Swartz, L., & Chiliza, B. (2015). Hearing their voices: The lived experience of recovery from first-episode psychosis in schizophrenia in South Africa. *International Journal of Social Psychiatry*, 61(1), 27–32. doi:10.1177/0020764014535753
- Deland, A. L., Karlsson, G., & Fatouros-Bergman, H. (2011). A phenomenological analysis of the psychotic experience. *Human Studies*, 34(1), 23–42. doi:10.1007/s10746-011-9174-0
- Dillon, J., & May, R. (2002). Reclaiming experience. *Clinical Psychology*, 17, 25–77.
- Dotchin, C., & Walker, R. (2012). The management of Parkinson's disease in sub-Saharan Africa. *Expert Review of Neurotherapy*, 12(6), 661–666. doi:10.1586/ern.12.52
- Dukas, C. (2013). *A feminist social constructionist analysis of depression in low-income South African women* (Doctoral dissertation). Stellenbosch University, Stellenbosch, South Africa.
- Ensink, K., Robertson, B. A., Ben-Arie, O., Hodson, P., & Tredoux, C. (1998). Expression of schizophrenia in black Xhosa-speaking and white English-speaking South Africans. *South African Medical Journal*, 88, 883–887. Retrieved from [https://www.researchgate.net/profile/Oved\\_Ben-Arie/publication/13585991\\_Experssion\\_of\\_schizophrenia\\_in\\_black\\_Xhosa-speaking\\_and\\_white\\_English-speaking\\_South\\_Africans/links/0fcfd5057bfe0e31d3000000.pdf](https://www.researchgate.net/profile/Oved_Ben-Arie/publication/13585991_Experssion_of_schizophrenia_in_black_Xhosa-speaking_and_white_English-speaking_South_Africans/links/0fcfd5057bfe0e31d3000000.pdf)
- Erikson, K. T. (1957). Patient role and social uncertainty: A dilemma of the mentally ill. *Psychiatry*, 30, 263–274. Retrieved from <https://scholar.google.co.za/scholar?q=Erikson%2C+K.+T.+%281957%29.+Patient+role+and+s>

- ocial+uncertainty%3A+A+dilemma+of+the+mentally+ill.+Psychiatry%2C+30%2C+263%E2%80%93274.&btnG=&hl=en&as\_sdt=0%2C5
- Estroff, S. E. (1989). Self, identity, and subjective experiences of schizophrenia: In search of the subject. *Schizophrenia Bulletin*, 15(2), 189–196. doi:10.1093/schbul/15.2.189
- Estroff, S. E. (2004). Subject/subjectivities in dispute: The poetics, politics, and performance of first-person narratives of people with schizophrenia. In J. H. Jenkins & R. J. Barrett (Eds.), *Schizophrenia, culture, and subjectivity: The edge of experience*. Cambridge: Cambridge University Press.
- Fernandez-Ballesteros, R. (2003). *Encyclopedia of psychological assessment*. London: Sage Publications.
- Field, M. J. (1960). *Search for security: An ethno-psychiatric study of rural Ghana*. London: Faber and Faber.
- Field, M. J. (1968). Chronic psychosis in rural Ghana. *British Journal of Psychiatry*, 114(506), 31–33. doi:10.1192/bjp.114.506.31
- Fish, B., & Kendler, K. S. (2005). Abnormal infant neurodevelopment predicts schizophrenia spectrum disorders. *Journal of Child and Adolescent Psychopharmacology*, 15, 348–361. doi:10.1089/cap.2005.15.348.
- Fisher, L., & Embree, L. (Eds.). (2000). *Feminist phenomenology*. Netherlands: Kluwer Academic Publishers.
- Flanagan, E. H., Davidson, L., & Strauss, J. S. (2010). The need for patient subjective data in the DSM and ICD. *Psychiatry*, 73, 297–307. doi:10.1521/psyc.2010.73.4.297
- Flanagan, E. H., Solomon, L. A., Johnson, A., Ridgway, P., Strauss, J. S., & Davidson, L. (2012). Considering the DSM: The personal experience of schizophrenia in relation to the DSM-IV-TR

- criteria. *Psychiatry*, 75(4), 375–386. Retrieved from <http://www.tandfonline.com/doi/abs/10.1521/psyc.2012.75.4.375>
- Flyvberg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry*, 12(2), 219–245.
- Forchuk, C., Jewell, J., Tweedell, D., & Steinnagel, L. (2003). Reconnecting: The client experience of recovery from psychosis. *Perspectives in Psychiatric Care*, 39(4), 141–150.  
doi:10.1111/ppc.2003.39.issue-4
- Foucault, M. (1963). *The birth of the clinic: An archaeology of medical perception*. London: Routledge.
- Freeman, D. (2007). Suspicious minds: The psychology of persecutory delusions. *Clinical Psychology Review*, 27(4), 425–457. doi:10.1016/j.cpr.2006.10.004
- Frosch, J. (1983). *The psychotic process*. New York: International Universities Press.
- Frosch, S. (1999). *The politics of psychoanalysis*. London: Palgrave Macmillan.
- Frosch, S. (2006). *For and against psychoanalysis*. London: Routledge.
- Frosch, S., Phoenix, A., & Pattman, R. (2000). But it's racism I really hate. *Psychoanalytic Psychology*, 17, 225–242. doi:10.1037/0736-9735.17.2.225
- Frosch, S., & Saville Young, L. (2008). Psychoanalytic approaches to qualitative psychology. In W. Stainton Rogers & C. Willig (Eds.), *Handbook of Qualitative Research in Psychology*. London: Sage Publications.
- Fulford, K. W. M., & Hope, R. A. (1993). Psychiatric ethics: A bioethical ugly duckling? In G. Raanon (Ed.), *Principles of Health Care Ethics*. New York: Wiley.
- Gardner, K. N., & Nasrallah, N. A. (2015). Managing first-episode psychosis: An early stage of schizophrenia with distinct treatment needs. *Current Psychiatry*, 14(5), 32–40. Retrieved from

- <https://www.questia.com/library/journal/1G1-415108266/managing-first-episode-psychosis-an-early-stage-of>
- Garety, P. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological Medicine*, 31, 189–195. doi:10.1017/S0033291701003312
- Garrett, M., & Turkington, D. (2011). CBT for psychosis in a psychoanalytic frame. *Psychosis*, 3(1), 2–13. doi:10.1080/17522439.2010.544403
- Gee, L., Pearce, E., & Jackson, M. (2003). Quality of life in schizophrenia: A grounded theory approach. *Health and Quality of Life Outcome*, 1, 31. doi:10.1186/1477-7525-1-31
- Geekie, J., Randal, P., Lampshire, D., & Read, J. (2012). *Experiencing psychosis: Personal and professional perspectives*. Hove: Routledge.
- Geekie, J., & Read, J. (Eds.). (2009). *Making sense of madness: Contesting the meaning of schizophrenia*. East Sussex: Routledge.
- Gillespie, R., & Gerhardt, C. (1995). Social dimensions of sickness and disability. In G. Moon & R. Gillespie (Eds.), *Society and health* (pp. 79–94). New York: Routledge.
- Gilligan, J. (2003). Shame, guilt, and violence. *Social Research: An International Quarterly*, 70(4), 1149–1180. Retrieved from <http://www.jstor.org/stable/40971965>
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597–607. Retrieved from <http://nsuworks.nova.edu/tqr/vol8/iss4/6>
- Greenwood, D. J., & Levin, M. (1998). *Social research for social change*. Thousand Oaks: Sage Publications.
- Gwyn, R. (2002). *Communicating health and illness*. Gateshead: Athenaem Press.

- Hamann, J., Cohen, R., & Leucht, S. (2007). Shared decision making and long-term outcome in schizophrenia treatment. *Journal of Clinical Psychiatry*, 68, 992–997. Retrieved from <http://www.psychiatrist.com/jcp/article/pages/2007/v68n07/v68n0703.aspx>
- Hamann, J., Mendel, R., & Schebitz, M. (2010). Can psychiatrists and neurologists predict their patients' participation preferences? *Journal of Nervous Mental Disorders*, 198, 309–311. doi:10.1097/NMD.0b013e3181d6128c
- Hamman, C., & Kruger, L. M. (forthcoming). The subjective experience of individuals diagnosed with schizophrenia in South Africa.
- Hare-Mustin, R. T., & Marecek, J. (1990). Gender and the meaning of difference: Postmodernism and psychology. In R. T. Hare-Mustin & J. Marecek (Eds.), *Making a difference: Psychology and the construction of gender* (pp. 22–64). London: Yale University Press.
- Henwood, K., & Pigeon, N. (2003). Grounded theory in psychological research. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative Research in Psychology: Expanding Perspectives in Methodology and Design* (pp. 131–155). Washington: American Psychological Association.
- Herbst, E. (2006). *The illness experience of HIV-infected low-income coloured mothers in the winelands: theoretical and practical implications* (Doctoral dissertation). Stellenbosch University, Stellenbosch, South Africa.
- Hirschfeld, R., Smith, J., Tower, P., & Griffin, C. (2005). What do psychotic experiences mean for young men? A qualitative investigation. *Psychology and Psychotherapy: Theory, Research and Practice*, 78, 249–270. doi:10.1348/147608305X25865
- Holmes, J. (2000). Narrative in psychiatry and psychotherapy: The evidence? *Medical Humanities*, 26(2), 92–96. doi:10.1136/mh.26.2.92



- Hornstein, G. A. (2002). Narratives of madness as told from within. *Chronicle of Higher Education*, 48, 7–10. Retrieved from [https://www.researchgate.net/profile/Gail\\_Hornstein/publication/265242569\\_Narratives\\_of\\_Madness\\_as\\_Told\\_From\\_Within/links/54b012e20cf220c63ccddc4b.pdf](https://www.researchgate.net/profile/Gail_Hornstein/publication/265242569_Narratives_of_Madness_as_Told_From_Within/links/54b012e20cf220c63ccddc4b.pdf)
- Hornstein, G. A. (2013). Whose account matters? A challenge to feminist psychologists. *Feminism & Psychology*, 23(1), 29–40. Retrieved from [https://www.researchgate.net/profile/Gail\\_Hornstein/publication/258137037\\_Whose\\_account\\_matters\\_A\\_challenge\\_to\\_feminist\\_psychologists/links/54de4be10cf2953c22ae463b.pdf](https://www.researchgate.net/profile/Gail_Hornstein/publication/258137037_Whose_account_matters_A_challenge_to_feminist_psychologists/links/54de4be10cf2953c22ae463b.pdf)
- Huffer, L. (2009). *Mad for Foucault: Rethinking the foundations of queer theory*. New York: Columbia University Press.
- Hugo, C. J., Boshoff, D. E. L., Traut, A., Zungu-Dirwayi, N., & Stein, D. J. (2003). Community attitudes toward and knowledge of mental illness in South Africa. *Social Psychiatry and Psychiatric Epidemiology*, 38(12), 715–719. doi:10.1007/s00127-003-0695-3
- Hutchby, I., & Wooffitt, R. (2002). *Conversation analysis: Principles, practices and applications*. Cambridge: Policy Press.
- Hyden, L. (1997). Illness and narrative. *Sociology of Health and Illness*, 19(1), 48–69. doi:10.1111/j.1467-9566.1997.tb00015.x
- Jackson, C., & Iqbal, Z. (2000). Psychological adjustment to early psychosis. In M. Birchwood, D. Fowler, & C. Jackson (Eds.), *Early intervention in psychosis* (pp. 64–100). Chichester: John Wiley & Sons.
- Janesick, V. J. (2000). The choreography of qualitative research design. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 379–399). London: Sage Publications.

- Janssen, I., Hanssen, M., & Bak, M. (2003). Discrimination and delusional ideation. *British Journal of Psychiatry*, 182, 71–76. doi:10.1192/bjp.182.1.71
- Jansson, L. B., & Parnas, J. (2007). Competing definitions of schizophrenia: What can be learned from polydiagnostic studies? *Schizophrenia Bulletin*, 33, 1178–1200. doi:10.1093/schbul/sbl065
- Jenkins, J. H., & Barrett, R. J. (Eds.). (2004). *Schizophrenia, culture and subjectivity*. New York: Cambridge University Press.
- Joseph, J. (2004). Schizophrenia and heredity: Why the emperor has no genes. In J. Read, L. R. Mosher, & R. P. Bentall (Eds.), *Models of madness: Psychological, social and biological approaches to schizophrenia*. Hove: Brunner-Routledge.
- K, S., & Duncan, M. (2006). Psychiatric disability and social change: An insider perspective. In *Disability and social change: A South African agenda* (pp. 291–310). Cape Town: HSRC Press.
- Kakuma, R., Kleintjies, S., Lund, C., Drew, N., Green, A., & Flisher, A. J. (2010). Mental Health Stigma: What is being done to raise awareness and reduce stigma in South Africa? *African Journal of Psychiatry*, 13(2). Retrieved from <http://www.ajol.info/index.php/ajpsy/article/view/54357>
- Kantrowitz, J. (2006). *Writing about patients: Responsibilities, risks and ramifications*. Virginia: The Other Press.
- Kaplan, H. I., & Sadock, B. J. (1995). *Kaplan and Sadock's comprehensive textbook of psychiatry* (6th ed.). Baltimore: Williams and Wilkins.
- Karlsen, N., & Nazroo, J. (2002). Relation between racial discrimination, social class and health among ethnic minority groups. *American Journal of Public Health*, 92, 624–631. doi:10.2105/AJPH.92.4.624

- Karp, D. A., & Birk, L. B. (2013). Listening to voices: Patient experience and the meanings of mental illness. In C. S. Aneshensel, J. C. Phelan, & A. Bierman (Eds.), *Handbook of the sociology of mental health* (pp. 23–40). Netherlands: Springer Science + Business Media.
- Kelleher, L., & Cannon, M. (2011). Psychotic-like experiences in the general population: Characterizing a high-risk group for psychosis. *Psychological Medicine*, 41(1), 1–6. doi:10.1017/S0033291710001005
- Khamker, N. (2015). First episode schizophrenia. *South African Family Practice*, 57(5), 29–33. Retrieved from <http://www.ajol.info/index.php/safp/article/view/125834>
- Kilkku, N., Munnukka, T., & Lehtinen, K. (2003). From information to knowledge: The meaning of information-giving to patients who had experienced first-episode psychosis. *Journal of Psychiatric and Mental Health Nursing*, 10(1), 57–64. doi:10.1046/j.1365-2850.2003.00536.x
- Kirmayer, L. J. (1988). Mind and body as metaphors: Hidden values in biomedicine. In *Biomedicine examined*. Netherlands: Kluwer.
- Kirmayer, L. J., Lemelson, R., & Cummings, C. A. (Eds.). (2015). *Re-envisioning psychiatry: Cultural phenomenology, critical neuroscience and global mental health*. New York: Cambridge University Press.
- Klein, M. (1935). A contribution to the psychogenesis of manic-depressive states. *International Journal of Psychoanalysis*, 16, 145–174. Retrieved from <http://search.proquest.com/openview/edc3d8e682424f6457486feab6093d82/1?pq-origsite=gscholar&cbl=1818729>
- Kleinman, A. (1988a). *Rethinking psychiatry: From cultural category to personal experience*. New York: The Free Press.

- Kleinman, A. (1988b). *The illness narratives: Suffering, healing and the human condition*. London: Harper Collins.
- Kleinman, A. (2015). Foreword. In *Re-envisioning psychiatry: Cultural phenomenology, critical neuroscience, and global mental health* (pp. xvii–xix). New York: Cambridge University Press.
- Koreen, A. R., Siris, S. G., Chakos, M., Alvir, J., Mayerhoff, D., & Lieberman, J. (1993). Depression in first-episode schizophrenia. *American Journal of Psychiatry*, 150, 1643–1648.  
doi:10.1176/ajp.150.11.1643
- Kotze, A. M. E., Van Delft, W. F., & Roos, J. L. (2010). Continuity of care of outpatients with schizophrenia in Pretoria. *South African Journal of Psychiatry*, 16(3), 80–83. Retrieved from <http://www.ajol.info/index.php/sajpsyc/article/view/68833>
- Kring, A. M., & Germans, M. K. (2004). Subjective experience of emotion in schizophrenia. In J. H. Jenkins & R. J. Barrett (Eds.), *Schizophrenia, culture, and subjectivity: The edge of experience*. Cambridge: Cambridge University Press.
- Kring, A. M., & Moran, E. K. (1993). Emotional response deficits in schizophrenia: Insights from affective science. *Schizophrenia Bulletin*, 34(5), 819. doi:10.1093/schbul/sbn071
- Kruger, L. M. (2015). In defense of Dora: Of mouths, melancholia and madness. Presented at the Cape Town Society for Psychoanalytic Psychotherapy Public Lecture, Cape Town, South Africa.
- Kruger, L. M., & Lourens, M. (2015). Motherhood and the “madness of hunger”: “...want almal vra vir my vir ‘n stukkie brood” (“...because everyone asks me for a little piece of bread”). *Culture, Medicine and Psychiatry*, 40(1), 124–143. doi:10.1007/s11013-015-9480-5
- Kruger, L. M., Van Straaten, K., Taylor, M., Lourens, M., & Dukas, C. (2014). The melancholy of murderous mothers: Depression and the medicalization of women’s anger. *Feminism & Psychology*, 24(4), 461–478. doi:10.1177/0959353514539653

- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks: Sage Publications.
- La Vita, M. (2016, December 2). Die skoonheid en verskrikking van waansin. *Netwerk24*. Retrieved from <http://www.netwerk24.com/Stemme/Profiele/die-schoonheid-en-verskrikking-van-waansin-20161202>
- Laing, R. D. (1960). *The divided self: An existential study in sanity and madness*. Harmondsworth: Penguin.
- Larsen, J. A. (2004). Finding meaning in first episode psychosis: Experience, agency and cultural repertoire. *Medical Anthropology Quarterly*, 18, 447–471. doi:10.1525/maq.2004.18.4.447
- Lesch, E. (2000). *Female adolescent sexuality in a Coloured community* (Doctoral dissertation). Stellenbosch University, Stellenbosch, South Africa.
- Lesko, N. (2001). *Act your age!: A cultural construction of adolescence*. New York: Routledge.
- Lorem, G. F., Frafjord, J. S., Steffensen, M., & Wang, C. E. A. (2014). Medication and participation: A qualitative study of patient experiences with antipsychotic drugs. *Nursing Ethics*, 21(3), 347–358. doi:10.1177/0969733013498528
- Lourens, M. (2014). *The nature of the relationship between depressed mothers and their children and the effect thereof on the development and experience of maternal depression: Perspectives from a low-income South African community* (Master's thesis). Stellenbosch University, Stellenbosch, South Africa.
- Lund, C., Oosthuizen, P., Flisher, A., Emsley, R., Stein, D., Botha, U., ... Joska, J. (2010). Pathways to inpatient mental health care among people with schizophrenia spectrum disorders in South Africa. *Psychiatric Services*, 61(3). doi:10.1176/appi.ps.61.3.235

- Lund, C., Petersen, I., Kleintjes, S., & Bhana, A. (2012). Mental health services in South Africa: Taking stock. *African Journal of Psychiatry*, 15(6). doi:10.4314/ajpsy.v15i6.48
- Lupton, D. (1997). Foucault and the medicalisation critique. In A. Petersen & R. Bunton (Eds.), *Foucault, health and medicine* (pp. 94–110). London: Routledge.
- Lysaker, P. H., Hunter, N. L., Strasburger, A. M., & Davis, L. W. (2005). Reported history of child sexual abuse in schizophrenia: associations with heightened levels of hallucinations and anxiety and poorer participation over four months in vocational rehabilitation. *The Journal of Nervous and Mental Disease*, 193, 790–795. Retrieved from [http://journals.lww.com/jonmd/Abstract/2005/12000/Reported\\_History\\_of\\_Child\\_Sexual\\_Abuse\\_in.3.aspx](http://journals.lww.com/jonmd/Abstract/2005/12000/Reported_History_of_Child_Sexual_Abuse_in.3.aspx)
- Lysaker, P. H., & Lysaker, J. T. (2008). *Schizophrenia and the fate of the self*. New York: Oxford University Press.
- Lysaker, P. H., & Lysaker, J. T. (2010). Schizophrenia and alterations in self-experience: A comparison of 6 perspectives. *Schizophrenia Bulletin*, 36(2), 331–340. doi:10.1093/schbul/sbn077
- Macleod, C. (2002). Deconstructive discourse analysis: Extending the methodological conversation. *South African Journal of Psychology*, 32(1), 17–25. doi:10.1177/008124630203200103
- Madriz, E., Denzin, N. K., & Lincoln, Y. S. (2000). Focus groups in feminist research. In *Handbook of qualitative research* (pp. 940–944). London: Sage Publications.
- Mason, J. (2002). *Qualitative researching*. London: Sage Publications.
- Mauthner, N., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413–431. Retrieved from [http://www.depts.ttu.edu/education/our-people/Faculty/additional\\_pages/duemer/epsy\\_6305\\_class\\_materials/Mauthner-Natasha-S-Doucet-Andrea-2003.pdf](http://www.depts.ttu.edu/education/our-people/Faculty/additional_pages/duemer/epsy_6305_class_materials/Mauthner-Natasha-S-Doucet-Andrea-2003.pdf)

- May, R. (2003). Understanding psychotic experience and working toward recovery. Retrieved May 31, 2016, from [www.brad.ac.uk/acad/health/research/cccmh/articles](http://www.brad.ac.uk/acad/health/research/cccmh/articles)
- Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M., & Bradshaw, D. (2009). The burden of non-communicable diseases in South Africa. *The Lancet*, 374(9693), 934–947. doi:10.1016/S0140-6736(09)61087-4
- Mayosi, B. M., Lawn, J. E., Van Niekerk, A., Bradshaw, D., Abdool Karim, S. S., & Coovadia, H. M. (2012). Health in South Africa: Changes and challenges since 2009. *Lancet South African Team*, 380(9858), 2029–2043. doi:10.1016/S0140-6736(12)61814-5
- Mbana, M. I., Niehaus, D. J., Mzamo, N. C., Wessels, C. J., Allen, A., Emsley, R. A., & et al. (2002). Attitudes towards and beliefs about schizophrenia in Xhosa families with affected probands. *Curationis*, 1, 69–73. doi:10.4102/curationis.v25i1.718
- Mbanga, N. I., Niehaus, D. J., Mzamo, N. C., Wessels, C. J., Allen, A., Emsley, R. A., & Stein, D. J. (2002). Attitudes towards and beliefs about schizophrenia in Xhosa families with affected probands. *Curationis*, 1, 69–73.
- McGlashan, T. H., & Hoffman, R. E. (2000). Schizophrenia as a disorder of developmentally reduced synaptic connectivity. *Archive of General Psychiatry*, 57, 637–648. doi:10-1001/pubs.Arch Gen Psychiatry-ISSN-0003-990x-57-7-ynv9397
- McGrath, J., Saha, S., Welham, J., El Saadi, O., MacCauley, C., & Chant, D. (2004). A systematic review of the incidence of schizophrenia: The distribution of rates and the influence of sex, urbanicity, migrant status and methodology. *BMC Psychiatry*, 2, 13. doi:10.1186/1741-7015-2-

- McKenzie, K., & Shah, J. (2015). Understanding the social etiology of psychosis. In *Re-envisioning psychiatry: Cultural phenomenology, critical neuroscience and global mental health* (pp. 317–342). New York: Cambridge University Press.
- McLeod, J. (2003). *Doing counselling research* (2nd ed.). London: Sage Publications.
- McWilliams, N. (2011). *Psychoanalytic diagnosis: Understanding personality structure in the clinical process* (2nd ed.). New York: Guilford Press.
- Mertens, D. M. (1998). *Research methods in education and psychology: Integrating diversity with quantitative and qualitative approaches*. Thousand Oaks: Sage Publications.
- Mestdag, A., & Hansen, B. (2014). Stigma in patients with schizophrenia receiving community mental health care: A review of qualitative studies. *Social Psychiatry and Psychiatric Epidemiology*, 49(1), 79–87. doi:10.1007/s00127-013-0729-4
- Michelle, L., Campbell, C., & Morrison, A. P. (2007). The subjective experience of paranoia: Comparing the experiences of patients with psychosis and individuals with no psychiatric history. *Psychology and Psychotherapy: Theory, Research and Practice*, 14, 63–77. doi:10.1002/cpp.510
- Mirowsky, J., & Ross, C. E. (1983). Paranoia and the structure of powerlessness. *American Sociological Review*, 48(229–238). Retrieved from <http://www.jstor.org/stable/2095107>
- Molefi, S. (2009). *Families' experiences with schizophrenia* (Master's thesis). Stellenbosch University.
- Moller, P., & Husby, R. (2000). The initial prodrome in schizophrenia: Searching for naturalistic core dimensions of experience and behaviour. *Schizophrenia Bulletin*, 26(1), 217–232. doi:10.1093/oxfordjournals.schbul.a033442
- Moncrieff, J. (2008). *The myth of the chemical cure: A critique of psychiatric drug treatment*. Hampshire: Palgrave Macmillan.



- Morgan, V. A., Waterreus, A., Carr, V., Castle, D., Cohen, M., Harvey, C., ... Jablensky, A. (2016). Responding to challenges for people with psychotic illness: Updated evidence from the Survey of High Impact Psychosis. *Australian & New Zealand Journal of Psychiatry*, 1–17.  
doi:10.1177/0004867416679738
- Morrison, A. P. (1984). Working with shame in the psychoanalytic treatment. *Journal of the American Psychological Association*, 32, 479–505. Retrieved from <http://psycnet.apa.org/psycinfo/1985-07249-001>
- Morrison, J. (2014). *The first interview* (4th ed.). New York: Guilford Press.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counselling psychology. *Journal of Counselling Psychology*, 52(2), 250–260. doi:10.1037/0022-0167.52.2.250
- Mosotho, L., Louw, D., & Calitz, F. J. W. (2011). Schizophrenia among Sesotho speakers in South Africa. *African Journal of Psychiatry*, 14(1). Retrieved from <http://www.ajol.info/index.php/ajpsy/article/view/65473>
- Motlana, L. M., Sokudela, B., Moraka, T., Roos, J. L., & Snyman, M. (2004). In touch with reality. *South African Psychiatry Review*, 7, 26–29. Retrieved from <http://www.ajol.info/index.php/ajpsy/article/view/30176>
- Mueser, K. T., & McGurk, S. R. (2004). Schizophrenia. *Lancet*, 363, 2063–2072. doi:10.1016/S0140-6736(04)16458-1
- Ng, R., Pearson, V., Lam, M., Law, C., Chiu, C., & Chen, E. (2008). What does recovery from schizophrenia mean? Perceptions of long-term patients. *International Journal of Social Psychiatry*, 54(2), 118–130. doi:10.1177/0020764007084600

- O'Donnell, B. F. (2007). Cognitive impairment in schizophrenia: A life span perspective. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 557–562.  
doi:10.1177/1533317507304745
- Owen, I. R. (1990). Social constructionism and the theory, practice and research of psychotherapy: A phenomenological psychology manifesto. *Boletín de Psicología*, 46, 161–186. Retrieved from <http://www.intentionalitymodel.info/pdf/SOCCONST.pdf>
- Oxford University Press. (2016). English Oxford Dictionaries. Retrieved November 15, 2016, from <https://en.oxforddictionaries.com>
- Painter, D. (2014). *At a loss for words: Some thoughts on language in/and social psychology*. Colloquium, Department of Psychology, Stellenbosch University, Stellenbosch, South Africa.
- Pao, P. (1977). On the formation of schizophrenic symptoms. *International Journal of Psycho-Analysis*, 58, 389–401. Retrieved from <http://search.proquest.com/openview/d06f9339cd383a72a812d8b01b65758d/1?pq-origsite=gscholar&cbl=1818729>
- Parker, I. (2005). *Qualitative psychology: Introducing radical research*. Maidenhead: Open University Press.
- Parker, I. (2006). Critical psychology and critical practice in Britain. *Annual Review of Critical Psychology*, 5, 89–100. Retrieved from [https://scholar.google.co.za/scholar?q=Parker%2C+I.+%282006%29.+Critical+psychology+and+critical+practice+in+Britain.+Annual+Review+of+Critical+Psychology%2C+5%2C+89%E2%80%93100.&btnG=&hl=en&as\\_sdt=0%2C5](https://scholar.google.co.za/scholar?q=Parker%2C+I.+%282006%29.+Critical+psychology+and+critical+practice+in+Britain.+Annual+Review+of+Critical+Psychology%2C+5%2C+89%E2%80%93100.&btnG=&hl=en&as_sdt=0%2C5)
- Patel, M. X. (2005). Why aren't depot antipsychotics prescribed more often and what can be done about it? *Advances in Psychiatric Treatment*, 11(3), 203–211. doi:10.1192/apt.11.3.203

- Patel, V. (2014). Rethinking mental health care: Bridging the credibility gap. *Intervention*, 12, 15–20.
- Retrieved from  
<http://www.interventionjournal.com/sites/default/files/Patel%202014%20I%20bridging%20credibility%20gap.pdf>
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks: Sage Publications.
- Psyche. (n.d.). Retrieved December 15, 2016, from <http://www.dictionary.com/browse/psyche>
- Read, J. (2005). The bio-bio-bio model of madness. *Psychologist Leicester*, 18(10), 596–597.  
 doi:10.1.1.466.6413
- Read, J., Mosher, L., & Bentall, R. (2004). *Models of madness*. Hove: Brunner-Routledge.
- Read, J., Perry, B. D., Moskowitz, A., & Connolly, J. (2001). The contribution of early traumatic events to schizophrenia in some patients: A traumagenic neurodevelopmental model. *Psychiatry*, 64, 319–345. doi:10.1521/psyc.64.4.319.18602
- Read, U. M., Doku, V. C. K., & Aikins, A. D. (2015). Schizophrenia and psychosis in West Africa. In E. Akyeampong, A. G. Hill, & A. Kleinman (Eds.), *The culture of mental illness and psychiatric practice in Africa* (pp. 73–111). Indiana: Indiana University Press.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20–23. Retrieved from <http://www.thepsychologist.org.uk/>
- Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24, 3345–343. doi:10.1037/h0095071
- Robbins, M. (1993). *Experiences of schizophrenia: An integration of the personal, scientific, and therapeutic*. New York: Guilford Press.
- Roe, D., & Davidson, L. (2005). Self and narrative in schizophrenia: Time to author a new story. *Medical Humanities*, 31(2), 89–94. doi:10.1136/jmh.2005.000214

- Roe, D., & Lachman, M. (2005). The subjective experience of people with severe mental illness: A potentially crucial piece of the puzzle. *Israelian Journal of Psychiatry*, 4, 223–230. Retrieved from <http://search.proquest.com/openview/f0934a8ee7494093a578c510b3be42e6/1?pq-origsite=gscholar>
- Romme, M., & Escher, S. (1993). *Accepting voices*. London: MND Publications.
- Rosenhan, D. L. (1973). On being sane in insane places. *Science*, 179(4070), 250–258.  
doi:10.1126/science.179.4070.250
- Rosenthal, R., & Rosnow, R. J. (2008). *Essentials of behavioural research: Method and data analysis* (3rd ed.). New York: McGraw-Hill.
- Russo, J. (2001). Reclaiming madness. In J. Read (Ed.), *Something inside so strong, strategies for surviving mental distress* (pp. 36–39). London: Mental Health Foundation.
- Sadock, B. J., Sadock, V. A., & Ruiz, P. (2014). *Kaplan and Sadock's synopsis of psychiatry: Behavioral sciences/clinical psychiatry*. Netherlands: Wolters Kluwer.
- Saks, E. (2007). *The center cannot hold: My journey through madness*. New York: Hyperion.
- Sass, L. (2007). Contradictions of emotion in schizophrenia. *Cognition & Emotion*, 21(2), 351–390.  
doi:10.1080/02699930600593313
- Schizophrenia Research Unit. (n.d.). Retrieved July 20, 2016, from <http://www.sun.ac.za/english/faculty/healthsciences/psychiatry/research/research-units/schizophrenia-research-unit>
- Seedat, S., Stein, D. J., Herman, A., Kessler, R., Sonnega, J., Heeringa, S., ... Williams, D. (2008). Twelve-month treatment of psychiatric disorders in the South African Stress and Health Study (World Mental Health Study Initiative). *Social Psychiatry and Psychiatric Epidemiology*, 43(11), 889–897. doi:10.1007/s00127-008-0399-9

- Semrand, E. V. (1960). *Teaching psychotherapy of psychotic patients*. New York: Grune & Stratton.
- Seu, B. I. (2006). Shameful selves: Women's feelings of inadequacy and constructed facades. *European Journal of Psychotherapy and Counselling*, 8(3), 285–303. doi:10.1080/13642530600878196
- Silverman, D. (1993). *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London: Sage Publications.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis. Theory, method and research*. London: Sage Publications.
- Sorsdahl, K. R., Flisher, A. J., Wilson, Z., & Stein, D. J. (2010). Explanatory models of mental disorders and treatment practices among traditional healers in Mpumalanga, South Africa. *African Journal of Psychiatry*, 13(4). Retrieved from <http://www.ajol.info/index.php/ajpsy/article/view/61878>
- Speed, E., Moncrieff, J., & Rapley, M. (Eds.). (2014). *De-medicalizing misery II: Society, politics and the mental health industry*. London: Palgrave Macmillan.
- Stanghellini, G., & Ballerini, M. (2007). Values in persons with schizophrenia. *Schizophrenia Bulletin*, 1, 131–141. doi:10.1093/schbul/sbl036
- Stikland Hospital. (n.d.). Retrieved July 14, 2016, from <http://www.stiklandhospital.co.za/>
- Stolorow, R., & Atwood, G. (1992). *Contexts of being: The intersubjective foundations of psychological life*. London: Analytic Press.
- Stoppard, J. M. (2000). *Understanding depression: Feminist social constructionist approaches*. London: Routledge.
- Sunkel, C. (2016). Living with...schizophrenia. *Mental Health Matters*, 3(1), 51–52. Retrieved from <https://scholar.google.co.za/scholar?q=Sunkel%2C+C.+%282016%29.+Living+with...schizophr>

enia.+Mental+Health+Matters%2C+3%281%29%2C+51%E2%80%9352.&btnG=&hl=en&as\_  
sdt=0%2C5

Swartz, L. (1998). *Culture and mental health: A South African view*. Cape Town: Oxford University Press.

Swartz, L., Gibson, K., Richters, T., & Gelman, T. (2002). *Reflective practice: Psychodynamic ideas in the community*. Cape Town: HSRC Press.

Swartz, S. (2012). *Writing psychotherapy*. Colloquium, Department of Psychology, University of Stellenbosch, Stellenbosch.

Swartz, S. (2013). Feminism and psychiatric diagnosis: Reflections of a feminist practitioner. *Feminism & Psychology*, 23(1), 41–48. Retrieved from

[https://scholar.google.co.za/scholar?q=Swartz%2C+S.+%282013%29.+Feminism+and+psychiatric+diagnosis%3A+Reflections+of+a+feminist+practitioner.+Feminism+%26+Psychology%2C+23%281%29%2C+41%E2%80%9348.&btnG=&hl=en&as\\_sdt=0%2C5](https://scholar.google.co.za/scholar?q=Swartz%2C+S.+%282013%29.+Feminism+and+psychiatric+diagnosis%3A+Reflections+of+a+feminist+practitioner.+Feminism+%26+Psychology%2C+23%281%29%2C+41%E2%80%9348.&btnG=&hl=en&as_sdt=0%2C5)

Swartz, S. (2015). *Homeless wanderers: Movement and mental illness in the Cape Colony in the nineteenth century*. Cape Town: UCT Press.

Szasz, T. (1961). *The myth of mental illness: Foundations of a theory of personal conduct*. New York: Hoeber-Harper.

Taylor, M., & Ng, K. Y. B. (2012). Should long-acting (depot) antipsychotics be used in early schizophrenia? A systematic review. *Australian & New Zealand Journal of Psychiatry*, 1–7. Retrieved from

<https://scholar.google.co.za/scholar?q=Taylor%2C+M.%2C+%26+Ng%2C+K.+Y.+B.+%282012%29.+Should+long-acting+%28depot%29+antipsychotics+be+used+in+early+schizophrenia%3F+A+systematic+re>

view.+Australian+%26+New+Zealand+Journal+of+Psychiatry%2C+1%E2%80%9337.&btnG=&hl=en&as\_sdt=0%2C5

- Terre Blanche, M., Durrheim, K., & Painter, D. (2006). *Research in practice: Applied methods for the social sciences*. Cape Town: University of Natal Press.
- Theberge, J., Williamson, K. E., & Aoyama, N. (2007). Longitudinal grey-matter and glutamatergic losses in first-episode schizophrenia. *British Journal of Psychiatry*, 191, 325–334. doi:10.1192/bjp.bp.106.033670
- Thomas, P., & Longden, E. (2013). Madness, childhood adversity and narrative psychiatry: caring and the moral imagination. *Medical Humanities*, 39(2), 119–125. doi:10.1136/medhum-2012-010268
- Tomecek, O. (1990). A personal commentary on “Schizophrenia as a brain disease.” *American Psychologist*, 45, 550–551. doi:10.1037/0003-066X.45.4.550
- Treichler, P. A. (1999). *How to have theory in an epidemic: Cultural chronicles of AIDS*. London: Duke University Press.
- Trotta, A., Di Forti, M., Mondelli, V., Dazzan, P., Pariante, C., David, A., ... Fisher, H. L. (2013). Prevalence of bullying victimisation amongst first-episode psychosis patients and unaffected controls. *Schizophrenia Research*, 150(1), 169–175. doi:10.1016/j.schres.2013.07.001
- Ucok, A., & Bikmaz, S. (2007). The effects of childhood trauma in patients with first-episode schizophrenia. *Acta Psychiatrica Scandinavica*, 116, 371–377. doi:10.1111/j.1600-0447.2007.01079.x
- Van Os, J., Hanssen, M., Bijl, R., & Vollebergh, W. (2001). Prevalence of psychotic disorder and community level of psychotic symptoms. *Archives of General Psychiatry*, 58, 663–663. doi:10.1001/archpsyc.58.7.663

- Van Zyl, P. (2016, February 11). Ons reis van 30 jaar met skisofrenie. *Huisgenoot*, pp. 6–8. South Africa.
- VanDenBos, G. R. (Ed.). (2015). *APA Dictionary of Psychology* (2nd ed.). Washington: American Psychological Association.
- Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., ... Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: A meta-analysis of patient-control, prospective- and cross-sectional cohort studies. *Schizophrenia Bulletin*, 38(4), 661–671. doi:10.1093/schbul/sbs050
- Vodusek, V. V., Parnas, J., Tomori, M., & Skodlar, B. (2014). The phenomenology of emotion experience in first-episode psychosis. *Psychopathology*, 47, 252–260. doi:10.1159/000357759
- Wagner, L. C., & King, M. (2005). Existential needs of people with psychotic disorders in Porto Alegre, Brazil. *British Journal of Psychiatry*, 186, 141–145. doi:10.1192/bjp.186.2.141
- Walsh, J., Hochbrueckner, R., Corcoran, J., & Spence, R. (2016). The lived experience of schizophrenia: A systematic review and meta-synthesis. *Social Work in Mental Health*, 14(6), 607–624. doi:10.1080/15332985.2015.1100153
- Walton, J. (2000). Schizophrenia and life in the world of others. *Canadian Journal of Nursing Research*, 32(3), 69–84.
- Watanabe, Y., & Kato, S. (2004). Recurrence of screwiness in chronic schizophrenia: Psychopathological considerations of Mitwelt oriented screwiness. *Seishin Shinkeigaku Zasshi*, 106(6), 712–722. Retrieved from <http://europepmc.org/abstract/med/15387266>
- Western Cape Department of Health. (2013). Healthcare 2030: The road to wellness (draft). Retrieved from <http://www.westerncape.gov.za/text/2013/October/health-care-2030-;9-oct-2013.pdf>



- Whitaker, R. (2010). *Anatomy of an epidemic: Magic bullets, psychiatric drugs, and the astonishing rise of mental illness in America*. New York: Crown.
- White, K. (2002). *Sociology of health and illness*. London: Sage Publications.
- White, R. (2004). Discourse analysis and social constructionism. *Nurse Researcher*, 12(2), 7–16.  
doi:10.7748/nr2004.10.12.2.7.c5935
- Whitely, R., & Crawford, M. (2005). Qualitative research in psychiatry. *Canadian Journal of Psychiatry*, 50, 108–114. Retrieved from  
<http://search.proquest.com/openview/1f0305ffe8a81445840226f9138033d2/1?pq-origsite=gscholar>
- Williams, C. C., & Collins, A. A. (1999). Defining new frameworks for psychosocial intervention. *Psychiatry*, 62(1), 61–78. doi:10.1521/00332747.1999.11024853
- Williams, C. C., & Collins, A. A. (2002). The social construction of disability in schizophrenia. *Qualitative Health Research*, 12(3), 297–309. doi:10.1177/104973202129119900
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Willig, C. (2013). *Introducing qualitative research in psychology: (3rd ed.)*. Buckingham: Open University Press.
- Willig, C., & Stainton-Rogers, W. (Eds.). (2008). *The SAGE handbook of qualitative research in psychology*. London: Sage Publications.
- Wood, M. E. (2013). *Life writing and schizophrenia: Encounters at the edge of meaning*. Netherlands: Editions Rodopi B. V.
- World Health Organization. (2001). *World Health Report 2001. Mental health: New understanding, new hope*. Geneva: WHO.

- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215–228.  
doi:10.1080/08870440008400302
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 235–251). London: Sage Publications.
- Yin, R. K. (1999). Enhancing the quality of case studies in health services research. *Health Services Research*, 34, 1209–1224. Retrieved from <http://www.hsr.org>
- Zubi, Y., & Connolly, P. (2013). Recollected experiences of first hospitalisation for acute psychosis among persons diagnosed with schizophrenia in South Africa. *South African Journal of Psychiatry*, 19(3), 81–85. doi:10.7196/sajp.399
- Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia. *Abnormal Psychology*, 86(2), 103–126. doi:10.1037/0021-843X.86.2.103

## **APPENDICES**

### **Appendix A1: Participant Recruitment Material**

Hello X

#### **Introduction and my details**

My name is Colette Hamman, a Psychology student from Stellenbosch University under supervision from Prof Lou-Marie Kruger. I am doing my research at the Research Unit nearby Stikland Hospital and that is where I got your number from. Thank you so much again for participating in the important Shared Roots study at the Schizophrenia Research Unit.

#### **Study details**

We have thought that in addition to what we already know and you have already shared, we would very much like to hear your own story in your own words of living with a diagnosis of schizophrenia. If you agree to participate in this study, you will be asked to participate in one individual interview of approximately an hour at a time that suits you best. This interview will take place at the Research Unit where you have previously been for the other study.

#### **Ethical issues**

I have ethical clearance for this study. This means that everything you say remains confidential and anonymous. You are free to decline to talk about certain issues during the interview that you are not comfortable with. A contribution will be made to your transport costs for the visit to the Research Unit.

a) Thank you very much for agreeing to participate in this study. Do you have any questions? (Arrange a date and time for the interview) See you on (day) at (time).

b) I understand that you do not want to participate in this study. Thank you for your time.

## **Appendix A2: Deelnemer Werwingsmateriaal**

Hello X

### **Inleiding en my besonderhede**

My naam is Colette Hamman, 'n Sielkunde student van Stellenbosch Universiteit onder supervisie van Prof. Lou-Marie Kruger. Ek doen my navorsing by die Navorsingseenheid naby Stikland Hospitaal en dit is waarvandaan ek u nommer gekry het. Weereens baie dankie vir u vorige deelname aan die belangrike 'Shared Roots' studie by die Skisofrenie Navorsingseenheid.

### **Studie besonderhede**

Ons het gedink, tesame met wat u alreeds gedeel het en wat ons alreeds weet, dat ons baie graag u eie storie van saamleef met 'n diagnose van skisofrenie in u eie woorde wil hoor. Indien u instem om aan die studie deel te neem, sal u gevra word om een individuele onderhoud van ongeveer 'n uur lank op 'n tyd wat u die beste pas by te woon. Hierdie onderhoud sal by die Navorsingseenheid waar u alreeds vir die vorige studie was, plaasvind.

### **Etiese aspekte**

Ek het etiese toestemming vir hierdie studie. Dit beteken dat alles wat u vir my sê vertroulik en anoniem sal bly. U is vry om te kies om nie oor sekere sensitiewe sake gedurende die onderhoud te praat nie. U sal 'n bydrae tot vervoerkostes vir die studiebesoek aan die Navorsingseenheid ontvang.

a) Baie dankie dat u instem om aan hierdie studie deel te neem. Het u enige vrae? (Reël 'n datum en tyd vir die onderhoud) Sien u op (dag) om (tyd).

b) Ek verstaan dat u nie aan die studie wil deelneem nie. Dankie vir u tyd.

**Appendix B1: Socio-demographic Questionnaire**

Name and surname: \_\_\_\_\_

Pseudonym: \_\_\_\_\_

Please answer the following questions:

1) Age: \_\_\_\_\_

2) Gender (M/F): \_\_\_\_\_

3) Home language: \_\_\_\_\_

4) Ethnic group (racial classification): \_\_\_\_\_

5) Religious group: \_\_\_\_\_

6) Marital/relationship status: \_\_\_\_\_

7) Level of education: \_\_\_\_\_

8) Occupation: \_\_\_\_\_

9) Estimated annual income: \_\_\_\_\_

10) Family members: \_\_\_\_\_

**Appendix B2: Sosio-demografiese Vraelys**

Naam en van: \_\_\_\_\_

Skuilnaam: \_\_\_\_\_

Beantwoord asseblief die volgende vrae:

- 1) Ouderdom: \_\_\_\_\_
- 2) Geslag (M/V): \_\_\_\_\_
- 3) Huistaal: \_\_\_\_\_
- 4) Etniese groep: \_\_\_\_\_
- 5) Godsdienstige groep: \_\_\_\_\_
- 6) Huweliks-/verhoudingstatus: \_\_\_\_\_
- 7) Vlak van opvoeding: \_\_\_\_\_
- 8) Beroep: \_\_\_\_\_
- 9) Geskatte jaarlikse inkomste: \_\_\_\_\_
- 10) Familielide: \_\_\_\_\_

## Appendix C1: Interview Schedule

### 1) Current symptoms and signs

- Hello x. I would like to start by asking you how you are doing/feeling today?  
*(Reflect participant's answers in an empathic way by using participant's own words and ask for more detail, but do not ask any leading questions.)*
- You have participated in a previous study here at the Research Unit and are now participating in this study, because the doctors say that you are diagnosed with schizophrenia. What do you think this is/means?
  - Symptoms
  - Vegetative symptoms*(Focus on each symptom separately and use symptoms as described by the participant to ask the next questions.)*

### 2) Episodes

- Would you say that you are currently not yourself/confused in the head/hearing voices/ill?  
*(Use the participant's own words.)*
- *(If answer is no):*
  - Tell me about when you first noticed that you were not feeling yourself/confused in the head/feeling ill?
    - When was that?
    - What did you notice first (symptoms)?
    - What did you think was happening to you?
    - How did you react?
    - How did you explain how you felt to other people?
  - When was the last time you felt like that?
  - And how do you feel now?
  - Why do you think you feel differently now?
- *(If answer is yes):*
  - For how long have you felt this way?
  - Tell me about the first time you felt like this?
    - When was that?
    - What did you notice first (symptoms)?
    - What did you think was happening to you?
    - How did you react?
    - How do you explain the way you are feeling to other people?

### 3) Stressors: participant

I would like us to stay at this first time when you have experienced these feelings and speak about what you think was happening in your life.

- Was anything happening then that might have started these feelings/symptoms?
- How did these things in your life affect you?
- Do you think these feelings/this illness can have something to do with something that might have happened earlier on in your life? Please tell me about it and how you think it can have something to do with the feelings/illness?

*(Try to get the participant's own theory about the diagnosis of schizophrenia. No leading questions, rather: tell me more, can you explain more?)*

#### 4) **Stressors: community**

- During these difficult times, who were the important people in your life?
- How did they react during these times?
- Why did they think you have developed these feelings/this illness?

*(Try to get a list of important people in the participant's life and their theories about the participant's diagnosis. No leading questions.)*

#### 5) **Treatment**

- Tell me about the time that you were diagnosed with schizophrenia.
  - Who diagnosed you?
  - How did it happen that you went to this person?
  - When was this?
  - How did the nurses or doctors explain what was happening to you?
  - What did this diagnosis mean to you?
  - How did you feel about this diagnosis?
- What treatment are you currently receiving?
- Can you please tell me more about your experience of this treatment?
  - How was this treatment plan explained to you?
  - How do you understand it?
  - How does it work?
  - How do you feel about this treatment?
  - How does it help you (wanted effects)?
  - What trouble do you have (side effects)? What kind of help/support/treatment would you rather have preferred?
- What other sort of treatments have you received?
- Can you tell me what you do to help yourself (coping skills)? An example?



- If you have to give advice to others with regards to what helps the best or what kind of help they should get - what will you say?

## 6) Consequences

- What sort of difficulties has this problem caused you?
  - Family
  - Friends
  - Job
  - Hobbies
  - Discomfort
- What positive things has this problem caused in your life?

## 7) Closure

Thank you. You have talked to me about very difficult things in your life.

- Is there anything else that you want to share with me?
- How do you feel now, as we get to the end of our first interview?

*(The interviewer might want to refer the participant by giving the supervisor's telephone number at the University, as well as the contact details of the Welgevallen Psychological Clinic in Stellenbosch, in case there are any questions or if the participant feels that she/he will need help during a later stage.)*

## Appendix C2: Onderhoudskedule

### 1) Huidige simptome en tekens

- Hello x. Ek wil graag begin deur te vra hoe dit vandag met u gaan/hoe u vandag voel?  
*(Reflekteer deelnemer se antwoorde in 'n empatiese wyse deur die deelnemer se eie woorde te gebruik en geen leidende vrae te vra nie.)*
- U het aan 'n vorige studie hier by die Navorsingseenheid deelgeneem en neem nou deel aan hierdie studie, omdat die dokters sê dat u met skisofrenie gediagnoseer is. Wat dink u is/betekén dit?
  - Simptome
  - Vegetatiewe simptome*(Fokus op elke simptoem apart en gebruik simptome soos gelys deur deelnemer om die volgende vrae te vra.)*

### 2) Episodes

- Sou u sê dat u tans nie uself is nie/stemme hoor/deurmekaar in die kop is/siek is? *(Gebruik deelnemer se eie woorde.)*
- *(Indien nee):*
  - Vertel my van die eerste keer toe u agter gekom het dat u nie uself is nie/deurmekaar voel in die kop/siek voel?
    - Wanneer was dit?
    - Wat het u eerste agtergekom (simptome)?
    - Wat het u gedink was besig om met u te gebeur?
    - Hoe het u gereageer?
    - Hoe het u aan ander mense verduidelik hoe u gevoel het?
  - Wanneer was die laaste keer wat u so gevoel het?
  - En hoe voel u nou?
  - Hoekom dink u voel u nou anders?
- *(Indien ja):*
  - Vir hoe lank voel u al so?
  - Vertel my van die eerste keer wat u so gevoel het?
    - Wanneer was dit?
    - Wat het u eerste agtergekom (simptome)?
    - Wat het u gedink was besig om met u te gebeur?
    - Hoe het u gereageer?
    - Hoe verduidelik u aan ander mense hoe u voel?

### 3) Stressors: deelnemer

Ek wil hê ons moet bly by die eerste keer wat u hierdie gevoelens ervaar het en praat oor wat u dink in u lewe aan die gebeur was.

- Was enigiets aan die gebeur in u lewe wat hierdie gevoelens/simptome kon veroorsaak het?
- Hoe het hierdie dinge in u lewe u geaffekteer?
- Dink u hierdie gevoelens/siekte kan iets te doen hê met iets wat vroeër in u lewe gebeur het? Vertel my asseblief meer hieroor en hoe u dink dit iets te doen kon hê met die gevoelens/siekte?

*(Probeer om die deelnemer se eie teorie oor skisofrenie te kry. Geen leidende vrae nie, eerder: vertel my meer, kan u uitbrei?)*

#### 4) Stressors: gemeenskap

- Gedurende hierdie moeilike tye, wie was die belangrike persone in u lewe?
- Hoe het hulle gereageer gedurende hierdie tye?
- Hoekom dink hulle het u hierdie gevoelens/siekte ontwikkel?

*(Probeer om 'n lys van belangrike persone in die deelnemer se lewe te kry asook hul teorieë oor die deelnemer se diagnose. Geen leidende vrae nie.)*

#### 5) Behandeling

- Vertel my van die keer toe u met skisofrenie gediagnoseer is.
  - Wie het u gediagnoseer?
  - Hoe het dit gebeur dat u by die persoon uitgekom het?
  - Wanneer was dit?
  - Hoe het die verpleegsters of dokters verduidelik wat besig was om met u te gebeur?
  - Wat het hierdie diagnose vir u beteken?
  - Hoe het u oor hierdie diagnose gevoel?
- Watter behandeling ontvang u tans?
- Kan u my meer vertel van u ervaring van die behandeling wat u tans ontvang?
  - Hoe was hierdie behandeling aan u verduidelik?
  - Hoe verstaan u dit?
  - Hoe werk dit?
  - Hoe voel u oor die behandeling?
  - Help dit u (gewenste effekte)?
  - Waarmee sukkel u (nadelige effekte)? Watter tipe hulp/ondersteuning/behandeling sou u verkies het?
- Watter ander behandeling het u al ontvang?
- Kan u my vertel wat u doen om uself te help (hanteringsvaardighede)? 'n Voorbeeld?

- Indien u vir ander mense raad moes gee in terme van wat help die beste of watter tipe hulp hulle moet kry – wat sou u sê?

## 6) Gevolge

- Watter moeilikhede het hierdie probleem vir u veroorsaak?
  - Familie
  - Vriende
  - Beroep
  - Stokperdjies
  - Ongemak
- Watter goeie dinge het hierdie probleem in u lewe veroorsaak?

## 7) Afsluiting

Dankie. U het oor moeilike dinge in u lewe met my gepraat.

- Is daar enigiets anders wat u met my wil deel?
- Hoe voel u nou, soos ons by die einde van ons eerste onderhoud kom?

*(Die onderhoudvoerder mag die deelnemer verwys deur die supervisor se telefoonnommer by die Universiteit te gee, sowel as die kontakbesonderhede van Welgevallen Sielkundige Kliniek in Stellenbosch, ingeval daar enige vrae is of die deelnemer voel dat hy/sy hulp sal nodig hê teen 'n later stadium.)*

## Appendix D1: Participant Informed Consent Form

### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**TITLE OF THE STUDY:** The subjective experience of individuals diagnosed with schizophrenia in South Africa

**REFERENCE NUMBER:** S16/07/131

**PRINCIPAL INVESTIGATOR OF STUDY:** Colette Hamman (under supervision of Prof Lou-Marie Kruger)

**ADDRESS:** Department of Psychology, Stellenbosch University, Wilcocks Building, Ryneveld Street, Stellenbosch, 7600

**CONTACT NUMBERS:**

Tel: 021 808 3461 (Psychology Department, Stellenbosch University)

Tel: 021 808 3460 (Prof Lou-Marie Kruger, Psychology Department)

Tel: 021 938 9207 (Health Research Ethics Committee, Stellenbosch University)

Tel: 021 910 3605 (Schizophrenia Research Unit, Stikland Hospital)

You are being invited to take part in a research project titled: **The Subjective Experience of Individuals Diagnosed with Schizophrenia in South Africa**. Please take some time to read the information presented here, which will explain the details of this study. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you can be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

**What is this study all about and why is it important?**

This study is about the lived experiences of people who have been diagnosed with schizophrenia. We want to have a better understanding of how individuals make sense of their experience of living with the diagnosis.

In the past 20 years, many advances have been made in our understanding of the biological mechanisms involved in the development of mental illnesses and how best to treat it. For example, a lot of attention has been paid to the use of different medications and how to administer it. However, less attention has been paid to peoples' stories and lived experiences of the diagnosis. Although knowledge about the biological aspects is important, a better understanding of peoples' experiences will help healthcare providers, like doctors, psychologists and nurses, to have a deeper understanding of patients' individual needs.

**Why have you been invited to participate?**

You have been invited to participate in this study, because you have been diagnosed with schizophrenia and you have already participated in a previous research project at the Schizophrenia Research Unit. You will therefore be able to provide us with your lived experience and understanding of a diagnosis of schizophrenia.

**Where will the study be conducted?**

The study will be conducted at the Schizophrenia Research Unit nearby Stikland Hospital in Bellville.

**What will your responsibilities be?**

You will be asked to participate in one individual interview. In this interview, you will be asked to talk about your experiences and understandings of a diagnosis of schizophrenia and how you experience the treatment and medication you receive. You will also be asked to tell the researcher a bit about your life story. Only you and the researcher will be present and you will be asked to talk to the researcher for approximately an hour at a time that suits you best.

**Will you benefit from taking part in this research?**

There will be no direct personal benefit from participating. However, you may help many patients in the future by helping healthcare providers gain a better understanding of how to best treat schizophrenia-related illnesses.

**Are there any risks involved in your taking part in this research?**

No, there are no risks involved in your taking part in this study. You are also free to decline to talk about issues during the interview that you are not comfortable to talk about. Should for some reason you feel that a topic discussed during the interview caused you emotional distress to the extent that you would like to talk to a professional, the researcher will assist you in finding free psychological services. Welgevallen Psychological Clinic in Stellenbosch provides free psychological services and you can contact them on 021 808 2696. Also, should you choose not to participate in this study, it will in no way jeopardize your participation in the other research projects at the Schizophrenia Research Unit.

**Who will have access to your medical records?**

We will not have access to your medical records or any other personal records. The interview will be audio-taped, transcribed word-for-word and kept confidential. Only the investigator and supervisor will have access to the transcriptions. Also, your name and surname will not be used in any of the data collected during the interviews. You will be given a pseudonym and this (not your name and surname) will be linked to your data.

Please note that the information collected during the interviews will be used in future academic outputs such as theses or publications in academic journals. However, your information is anonymous and no-one will be able to link the data collected through the interview with your name and surname.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study, but you will receive a contribution towards transport costs for each study visit to the Schizophrenia Research Unit.

**Is there anything else that you should know or do?**

- You can contact Colette Hamman via email on [16586360@sun.ac.za](mailto:16586360@sun.ac.za) or Prof Lou-Marie Kruger via email on [lkrug@sun.ac.za](mailto:lkrug@sun.ac.za) or telephonically at 021 808 3460 if you have any further queries or encounter any problems.

- You can contact the Health Research Ethics Committee at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

## Declaration by participant

By signing below, I ..... agree to take part in this research study entitled: *The Subjective Experience of Individuals Diagnosed with Schizophrenia in South Africa*.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that the interviews will be audio-taped and used **anonymously** in future academic outputs.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interest, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2016.

.....  
Signature of participant

.....  
Signature of witness

## Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2016.

.....  
Signature of investigator

.....  
Signature of witness



## Appendix D2: Deelnemer Toestemmingsvorm

### DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

**TITEL VAN DIE NAVORSINGSPROJEK:** Die subjektiewe ervaring van individue gediagnoseer met skisofrenie in Suid-Afrika

**VERWYSINGSNOMMER:** S16/07/131

**HOOFNAVORSEER VAN DIE STUDIE:** Colette Hamman (onder supervisie vanaf Prof. Lou-Marie Kruger)

**ADRES:** Department Sielkunde, Universiteit Stellenbosch, Wilcocks gebou, Ryneveldt straat, Stellenbosch, 7600

**KONTAKNOMMERS:**

Tel: 021 808 3461 (Department Sielkunde, Universiteit Stellenbosch)

Tel: 021 808 3460 (Prof. Lou-Marie Kruger, Department Sielkunde)

Tel: 021 938 9207 (Gesondheidsnavorsingsetiekkomitee, Universiteit Stellenbosch)

Tel: 021 910 3605 (Skisofrenie Navorsingseenheid, Stikland Hospitaal)

U word genooi om deel te neem aan 'n navorsingsprojek genaamd: **Die Subjektiewe Ervaring van Individue Gediagnoseer met Skisofrenie in Suid-Afrika**. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die besonderhede van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel daaroor uit te vra. Dit is baie belangrik dat u ten volle verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en u is vry om deelname te weier. U sal op geen wyse negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook enige tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

Hierdie navorsingsprojek is deur die **Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit Stellenbosch** goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

**Wat behels hierdie navorsingsprojek en hoekom is dit belangrik?**

Hierdie studie gaan oor die ervarings van mense wat met skisofrenie gediagnoseer is en daarmee saamleef. Ons wil beter verstaan hoe individue sin maak van hul ervarings van hierdie diagnose.

Gedurende die afgelope 20 jaar, is daar baie vordering gemaak in hoe die biologiese meganismes wat deel vorm van die ontwikkeling van geestesversteurings verstaan word en hoe om hierdie siektes op die beste manier te behandel. Baie aandag is byvoorbeeld gegee aan die gebruik van verskillende medikasies en hoe om dit toe te dien. Minder aandag is egter gegee aan mense se individuele stories en ervarings van saamleef met die diagnose. Al is kennis oor die biologiese aspekte belangrik, kan 'n beter begrip van mense se ervarings vir gesondheidsorgvoorsieners, soos dokters, sielkundiges en verpleegsters, help om pasiënte se individuele behoeftes beter te verstaan.

**Waarom is u genooi om deel te neem?**

U is genooi om aan hierdie studie deel te neem, omdat u met skisofrenie gediagnoseer is en alreeds gevra is om aan 'n vorige navorsingsprojek by die Skisofrenie Navorsingseenheid deel te neem. U sal dus vir ons kan vertel van u ervaring van saamleef met 'n diagnose van skisofrenie en hoe u hierdie diagnose verstaan.

**Waar sal die studie uitgevoer word?**

Die studie sal uitgevoer word by die Skisofrenie Navorsingseenheid naby Stikland Hospitaal in Belville.

**Wat sal u verantwoordelikhede wees?**

U sal gevra word om deel te neem aan een individuele onderhoud. In hierdie onderhoud sal u gevra word om te praat oor u ervarings en begrip van 'n diagnose van skisofrenie en hoe u die behandeling en medikasie wat u ontvang, ervaar. U sal ook gevra word om die navorser 'n bietjie meer van u lewensstorie te vertel. Slegs u en die navorser sal teenwoordig wees en u sal gevra word om met die navorser te praat vir ongeveer 'n uur op 'n tyd wat u die beste pas.

**Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?**

Daar sal geen direkte persoonlike voordele wees deur deel te neem aan die studie nie. U mag egter baie pasiënte in die toekoms help deur gesondheidsorgvoorsiensers te help om beter te verstaan hoe om skisofrenie-verwante siektes te behandel en te hanteer.

**Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?**

Nee, daar is geen risiko's verbonde aan u deelname aan die studie nie. U is ook vry om te kies om nie oor 'n aspek te praat wat u ongemaklik laat voel gedurende die onderhoud nie. Indien u voel dat 'n onderwerp wat gedurende die onderhoud bespreek is vir u emosionele ongemak veroorsaak het, tot 'n mate dat u met 'n professionele persoon wil praat, sal die navorser u help om gratis sielkundige dienste te vind. Welgevallen Sielkundige Kliniek in Stellenbosch bied gratis sielkundige dienste en u kan hulle by 021 808 2696 skakel. Ook, indien u nie wil deelneem aan hierdie studie nie, sal dit in geen manier u deelname aan die ander navorsingsprojek by die Skisofrenie Navorsingseenheid beïnvloed nie.

**Wie sal toegang hê tot u mediese rekords?**

Ons sal nie toegang hê tot u mediese rekords of enige ander persoonlike rekords nie. Die onderhoude sal opgeneem word, woord-vir-woord oorgeskryf word en vertroulik bly. Slegs die navorser en supervisor sal toegang hê tot die opnames. U naam en van sal ook nie in enige van die inligting wat gedurende die onderhoude ingesamel is, gebruik word nie. U sal 'n subjek identifikasienaam gegee word en dit (nie u naam en van nie) sal aan die inligting gekoppel word.

Neem asseblief kennis dat die inligting wat gedurende die onderhoude ingesamel is, in akademiese uitsette soos tesisse of publikasies in akademiese joernale gebruik mag word. U inligting is egter anoniem en niemand sal die inligting wat gedurende die onderhoud ingesamel is, kan koppel aan u naam en van nie.

**Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?**

U sal nie betaal word vir deelname aan die navorsingsprojek nie, maar u sal 'n bydrae tot u vervoerkostes vir elke besoek aan die Skisofrenie Navorsingseenheid by Stikland Hospitaal ontvang.

**Is daar enigiets anders wat u moet weet of doen?**

- U kan Colette Hamman per epos na [16586360@sun.ac.za](mailto:16586360@sun.ac.za) kontak of vir Prof. Lou-Marie Kruger per epos na [lkrug@sun.ac.za](mailto:lkrug@sun.ac.za) of per telefoon by 021 808 3460 kontak indien u enige verdere vrae het of enige probleme ondervind.
- U kan die Gesondheidsnavorsingsetiekkomitee administrasie by 021 938 9207 kontak indien u enige bekommernis of klagte het wat nie bevredigend deur u navorser hanteer is nie.
- U sal 'n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

## Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,  
....., om deel te neem aan 'n navorsingsprojek getiteld: *Die subjektiewe ervaring van individue gediagnoseer met skisofrenie in Suid-Afrika*.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae voldoende beantwoord is.
- Ek verstaan dat die onderhoude opgeneem gaan word en **anoniem** in toekomstige akademiese uitsette gebruik gaan word.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek op enige tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (plek) ..... op (datum) ..... 2016.

.....  
**Handtekening van deelnemer**

.....  
**Handtekening van getuie**

## Verklaring deur navorser

Ek (naam) ..... verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan  
.....
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.*)

Geteken te (plek) ..... op (datum) ..... 2016.

.....  
**Handtekening van navorser**

.....  
**Handtekening van getuie**

## Appendix E: Ethical Approval Notice



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

### Approval Notice Response to Modifications- (New Application)

15-Aug-  
2016  
Hamman,  
Colette C

**Ethics Reference #: S16/07/131**

**Title:** The subjective experience of individuals diagnosed with first-episode psychosis in schizophrenia in South Africa

Dear Miss Colette Hamman,

The **Response to Modifications - (New Application)** received on **04-Aug-2016**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **15-Aug-2016** and was approved.  
Please note the following information about your approved research protocol:

Protocol Approval Period: **15-Aug-2016 -14-Aug-2017**

Please remember to use your **protocol number** (**S16/07/131**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

#### **After Ethical Review:**

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

#### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western

Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

If you have any questions or need further assistance, please contact the HREC office at .

**Included Documents:**

Checklist.pdf  
20160805 MOD Protocol  
Protocol.pdf  
CV L Kruger.docx  
Protocol Synopsis.pdf  
IFC Eng and Afr 2016.pdf  
CV C Hamman.pdf  
20160805 MOD Cover letter  
Cover letter.pdf  
Declaration C Hamman.pdf  
Application form.pdf  
Declaration L Kruger.pdf

Sincerely,

Francis Masiye  
HREC Coordinator  
Health Research Ethics Committee 2



